

# **BARRIERS AND FACILITATORS THAT AFFECT ACCESS TO AN OUTPATIENT SPEECH-LANGUAGE THERAPY APHASIA CLINIC**

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of Speech and Language Therapy in the Department of Communication Disorders

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## **Abstract**

**Background:** Many barriers impact on access to services for adults with aphasia. Speech-language therapists need to provide accessible services for people with aphasia, if they hope to inform other service providers to do the same. Previous studies have identified some barriers and facilitators that may influence the participation of individuals with aphasia in outpatient speech-language therapy services, as part of the larger aims of those investigations. However, to date, no investigation has focused specifically on identifying barriers and facilitators that influence access to outpatient speech-language therapy services for adults with aphasia and for their family members.

The current study had two aims to address this gap in the literature:

1. To explore the barriers and facilitators that influence the access of adults with aphasia and their family members/friends to an outpatient speech-language therapy aphasia clinic, and;
2. To identify a consensus of the most important barriers and facilitators that influence access to an outpatient speech-language therapy aphasia clinic by adults with aphasia and their family members/friends.

**Method:** A modified Delphi technique was used with two rounds. In the first round, nine participants with aphasia participated in semi-structured interviews involving open-ended questions about perceived barriers and facilitators to accessing an outpatient speech-language therapy aphasia clinic. Nine family member/friend participants and two student speech-language therapy participants also completed qualitative written questionnaires involving the same open-ended questions. The data was analysed using qualitative content analysis and used to develop the questionnaire for the second-round. In the second round, the family member/friend participants and student speech-language therapy participants completed a written questionnaire to identify the most important barriers and facilitators identified in the first round. The researcher administered the same questionnaire face-to-face to the participants with aphasia. The results from round two were analysed to identify the most important barriers and facilitators that reached a consensus.



**Results:** Analysis of the data from round one revealed 23 barriers that fell in eight categories and 37 facilitators that fell in nine categories. In round two, only two of the 23 barriers were identified as being important by all three participant groups, whereas, 36 of the 37 facilitators were considered to be important.

**Conclusion:** The findings can be used to improve the development of more accessible outpatient speech-language therapy and other health services for individuals with aphasia and their families.

## **Introduction**

“Many people with disabilities do not have equal access to health care, education, and employment opportunities, do not receive the disability-related services that they require, and experience exclusion from everyday life activities” (World Health Organisation, 2011, p. 21). For those with aphasia, there are many barriers that impact on their access to services. While service providers have an obligation to be accessible to all in accordance with human rights law, they will require the guidance of professionals to advise on how best to achieve optimal communicative accessibility. Communication rehabilitation is usually the responsibility of the speech-language therapist, the health professional with expertise in the area of communication access. Speech-language therapists need to provide an example of accessible service provision for people with aphasia, if they hope to inform other service providers to do the same. This study aims to address this issue, and will focus on examining the barriers that people with aphasia and their families face when accessing an outpatient speech-language therapy service and the facilitators that support access to the same service.

This chapter outlines the key terms in the thesis (i.e. “aphasia,” “access,” “barriers and facilitators,” and “outpatient speech-language therapy service”), followed by a discussion of the previous research in the area. It concludes with a summary of the significance of the research and the aims of the current study.

### **What is aphasia?**

Aphasia is “an acquired selective impairment of language modalities and functions resulting from a focal brain lesion in the language-dominant hemisphere that affects the person’s communicative and social functioning, quality of life, and the quality of life of his or her relatives and caregivers” (Papathanasiou, Coppens, & Potagas, 2013). A recent study carried out over the course of one year found approximately one in three adult patients who had had a stroke had symptoms of aphasia upon discharge from hospital (Dickey et al., 2010). In New Zealand

specifically, it is estimated over 16,000 people are living with aphasia (Aphasia Association of New Zealand, 2014).

### **What is access?**

Access is described as an 'ill-defined' (Ashton et al., 2008) and "complex and multidimensional concept" (Gulliford et al., 2002). Therefore, there are many different definitions of access to health services. to date. For the purposes of this study, access to outpatient speech-language therapy services can be best defined as "the appropriate combination and deployment of resources to facilitate the processes of people [with communication deficits] entering, and moving through [the outpatient service] in order to achieve optimal outcomes" (Gulliford, Figueroa-Munoz, & Morgan, 2003, p. 9).

### **What are barriers and facilitators?**

This study is underpinned by the World Health Organisation's (WHO) International Classification of Functioning, Disability, and Health (ICF) (WHO, 2001), an established framework that describes the impact of a health condition on a person's everyday functioning. The ICF provides the basis for the identification of barriers and facilitators that people with aphasia encounter when accessing an outpatient speech-language therapy service. The ICF aims to provide a standard theoretical framework and classification system for health and disability, which can be applied to all people with any health condition, and applied to any physical, social or cultural setting. It is known as a 'biopsychosocial' model, meaning that it considers various domains of a person's health, integrating the medical model as well as the psychosocial model of disability. This particular model of disability was developed as a result of demand for a more holistic view of health assessment (Threats, 2007). The ICF conceptualises a person's level of functioning as a dynamic interaction between a person's health condition, personal factors, and environmental factors. Environmental factors are "all aspects of the external or extrinsic world that form the context of an individual's life and, as such, have an impact on that person's functioning" (WHO, 2001, p.213). According to the ICF, environmental factors can be categorised as barriers that limit or hinder a person's functioning, or facilitators that

support a person's functioning. It must be noted that a particular environmental factor may be either a facilitator or a barrier, depending on the circumstances (Threats, 2007).

Environmental factors will be encountered throughout the process of accessing a speech-language outpatient service. Therefore identification of the factors that are barriers and/or facilitators to access of this service for people with aphasia will be central to this study. An example of an environmental factor that may be a barrier may be health information that is not aphasia-friendly, while an example of an environmental factor that may be a facilitator may be a receptionist who is aware of aphasia and has the knowledge to communicate effectively with individuals with aphasia.

### **What is an outpatient speech-language therapy service?**

An outpatient service is a health service where the client typically spends time utilising the service and receiving treatment without requiring an overnight stay (The American Heritage Stedman's Medical Dictionary, 2014). For the purposes of this study, an outpatient speech-language therapy service refers to an outpatient service involving provided or directed by a speech-language therapist for a client with aphasia. The service may take place in a variety of locations including the client's home or rest home/residential facility, in an outpatient clinic or centre, or in the community. The specific outpatient speech-language therapy service that is the focus of this study is a university outpatient speech-language therapy service at the University of Canterbury (UC) in Christchurch, New Zealand.

### **Barriers to and facilitators for accessing services for individuals with aphasia**

The following literature review discusses and critiques the findings of relevant past studies that have examined barriers and facilitators to adults with aphasia and their family members, particularly with regards to accessing general community services, including health services. This review contains studies published in English only and identified in CINAHL, Web of Science, PsychINFO, and PubMed electronic databases. Further references were obtained from the citation lists of published journal articles. The terms used for the search were aphasia OR dysphasia OR

stroke AND speech AND (barrier\* OR facilitat\* OR access\*). The review includes research involving barriers to and facilitators for accessing the following services: community services for individuals with aphasia, inpatient health services for individuals with aphasia, outpatient health services for individuals with aphasia, outpatient speech-language therapy services for individuals with aphasia, and outpatient speech-language therapy services for family members of individuals with aphasia.

### **Barriers to and facilitators for accessing community services for individuals with aphasia**

Some studies have reported a few barriers and facilitators perceived by individuals with aphasia to influence their participation when accessing speech-language therapy services as part of larger investigations focusing on access to community services in general (Howe, 2006; Howe, Worrall, & Hickson, 2008a, 2008b; Le Dorze, Salois-Bellerose, Alepins, Croteau, & Hallé, 2014; Parr, 2004; Parr et al., 1997). For example, one barrier reported by individuals with aphasia included not being aware of whether additional speech-language therapy services were available in the community (Le Dorze et al., 2014), while in another study a facilitator included having different speech therapy fees charged depending on a person's income (Howe, 2006). Some of the barriers and facilitators perceived by individuals with aphasia in accessing other community services may also be applicable to speech-language therapy services. The following discussion highlights those important barriers and facilitators for adults with aphasia in relation to behaviours of communication partners, attitudes of other people, health-related information, signage, auditory and visual environment found in the research to date.

### ***Barriers and facilitators relating to communication behaviours that affect people with aphasia***

The availability of family members was found to be both a facilitator and a barrier for those with aphasia when accessing services (Howe et al., 2008b). This can include the family member speaking for the person with aphasia. Although this could help assist the person with aphasia in accessing what they need, other

situations may not allow them to speak for themselves, and other people may not address the person with aphasia directly, preferring to respond only to the accompanying person.

Communicating with those who are familiar to the person with aphasia was identified as a facilitator, as familiar communication partners are likely to have enhanced awareness as well as a better shared understanding of that person with aphasia (Baylor et al., 2011; Howe et al., 2008b).

Communication behaviours of other individuals such as service providers can be a barrier for people with aphasia, such as a fast rate of speech, not allowing the person with aphasia enough time to respond, and too many people involved during communication (Howe et al., 2008b; Parr, 2004; Parr et al., 1997). Communication partners who did not have the skills to communicate with those who have aphasia has also been reported to be a barrier (Le Dorze, Salois-Bellerose, Alepins, Croteau, & Hallé, 2014).

Facilitators include providing plenty of attention when listening to those with aphasia, giving plenty of time to respond (Howe et al., 2008b; Baylor et al., 2011), with the communication partner focussing on the content of what is being said, rather than the characteristics of how it is said (Baylor et al., 2011). One-to-one and small group settings were also identified to facilitate communication for those with aphasia (Howe et al., 2008b). A study that examined the use of communication partner training to increase facilitative communication behaviours found that this practice was effective and positive on individuals with aphasia (Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001).

### ***Barriers and facilitators relating to attitudes of others***

Negative individual and societal attitudes, including those of service providers, have also been reported to be significant barriers for people with aphasia (Brown et al., 2006; Howe et al., 2008b). Service provider attitudes such as lack of knowledge and awareness about aphasia were identified as a barrier (Flynn et al., 2009) (Brown et al., 2006; Howe et al., 2008b). This was also a key point raised by service providers themselves (Brown et al., 2006). Another study found that healthcare providers were not perceived to know about aphasia resources, highlighting a lack of awareness of aphasia even within the health sector (Hinckley et al., 2013). Increased

awareness of aphasia was reported by people with aphasia to be a facilitator (Howe et al., 2008b; Parr et al., 1997).

### ***Barriers and facilitators relating to health-related information***

When a family is affected by aphasia, they may search for aphasia resources to help manage the consequences of the communication difficulty (e.g., brochures showing available services, websites, and discharge recommendations). Less than 50% of people with aphasia may not be receiving written information about aphasia in the first place (Rose, Worrall, McKenna, Hickson, & Hoffmann, 2009), while written information about aphasia and stroke was considered to be helpful by participants in a study looking at the written information preferences of people with aphasia, especially at various stages after one month post-stroke (Rose, Worrall, Hickson, & Hoffmann, 2010). However, studies have found that reduced access to written information is reported to be an on-going barrier for people with aphasia, with the information often written at a level that is too difficult (Rose, Worrall, Hickson, & Hoffmann, 2011, 2012; Rose, Worrall, & McKenna, 2003; Worrall et al., 2005; Worrall et al., 2007). In addition, aphasia or speech-language resources were not found to be considerably easier to read than other health information materials (Aleigay, Worrall, & Rose, 2008). Facilitators for 'aphasia-friendly' written service information include using simplified language in larger print with plenty of white space (Brennan, Worrall, & McKenna, 2005), with the support of pictures or photographs where appropriate (Rose, Worrall, Hickson, & Hoffmann, 2012).

The availability of aphasia resources was also considered to be lacking, and difficult to access (Flynn, Cumberland, & Marshall, 2009; Hinckley, Hasselkus, & Ganzfried, 2013). This included information on websites that were not usually readily available (Worrall et al., 2007) or accessible to people with aphasia (Ghidella, Murray, Smart, McKenna, & Worrall, 2005). Research also found that people with aphasia did not agree with speech-language therapists on what was considered to be the characteristics of an accessible website (Ghidella et al., 2005), and found that those with aphasia could successfully participate in the creation and design of aphasia information websites (Kerr, Hilari, & Litosselti, 2010), highlighting the importance of including the expert individual with aphasia to overcome barriers.

### ***Barriers and facilitators relating to signage***

In order to access a service, a person with aphasia may need to read signs. Signage that is clear and colour coded was reported to be facilitative in a community environment for people with aphasia (Howe et al., 2008b). In large busy community areas such as transport terminals, people with aphasia reported that signage and information such as train details on a screen were difficult to interpret and that they would benefit from a simplified timetable (Ashton et al., 2008). People with aphasia found that taxis were easy to identify due to their distinctive signage, and consistent signage at departure points for buses and trains were described as a facilitator, however, the characteristics and formatting of what is considered to be aphasia-friendly signage were not explored (Ashton et al., 2008).

### ***Barriers and facilitators relating to the auditory and visual environment***

Noise levels are reported to be barrier for those with aphasia (Garcia et al., 2000; Howe et al., 2008b). Additionally, visual distractions have also been highlighted as a barrier for individuals with aphasia (Howe et al., 2008b).

### ***Barriers and facilitators relating to services, systems, and policies***

Many studies found that service systems, policies, and procedures hindered participation and access to services for people with aphasia, such as the availability of advocates who can assist them with accessing those services (e.g., legal proceedings (Howe et al., 2008b; Parr, 2004; Parr et al., 1997), or medical appointments (Le Dorze et al., 2014)). Access to public transport services were confounded by the mechanisms of the transport process, such as time constraints and requiring verbal communication with the bus driver to obtain a ticket (Ashton et al., 2008).

Research found that barriers to healthcare access that were considered unrelated to finances, correlated with barriers related to financial difficulties; such as the ability to afford therapy (Kullgren, McLaughlin, Mitra, & Armstrong, 2012). It was also found that barriers unrelated to finances are not considered as strongly as financial barriers during the policy-making process (Kullgren et al., 2012).



### **Barriers to and facilitators for accessing inpatient health services for individuals with aphasia**

In recent years, O'Halloran and colleagues (O'Halloran, Grohn, et al., 2012; O'Halloran et al., 2011; O'Halloran, Worrall, & Hickson, 2012) have investigated communicative access for patients with strokes and patients with communication disabilities in inpatient hospital services. These studies have used methods such as participant observation (O'Halloran et al., 2011), and qualitative metasynthesis (O'Halloran, Grohn, et al., 2012). Some barriers were identified for individuals with communication disabilities, such as a lack of communication aids and equipment in the inpatient setting and the healthcare provider's inadequate communication skills (O'Halloran, Grohn, et al., 2012). Other frequently reported barriers found in the literature included inadequate discharge plans or inappropriate discharge home, which could lead to negative consequences regarding participation after discharge (Hemsley, Werninck, & Worrall, 2013). Recently, O'Halloran, Lee, Rose, and Liamputtong (2014) investigated the perspectives of speech-language therapists about their role in creating communicatively accessible environments for individuals with communication disabilities. The study focused on the therapists' perceptions of their role in this process rather than on identifying barriers and facilitators to access. In addition, the focus of the study was on individuals with communication disabilities in general, rather than specifically on individuals with aphasia.

### **Barriers to and facilitators for accessing outpatient health services for individuals with aphasia**

Attendance at various community organisations such as local stroke or aphasia groups, were described to be facilitative, as participants reported they had the opportunity to practice speaking and felt their communication abilities had progressed due to their attendance and participation (Le Dorze et al., 2014; Rotherham, Howe, & Tillard, 2015). In addition, people with aphasia reported feeling "welcomed, protected, included, and unconcerned about being judged by others within the organisational setting" (Le Dorze et al., 2014). Furthermore, people with aphasia reported feeling like they were part of a large family, invoking a sense of

belonging, and felt supported by others who were in similar situations to them (Le Dorze et al., 2014; Rotherham et al., 2015).

A lack of information about aphasia resources and other written materials related to outpatient services was reported to be a barrier in current research (Hinckley et al., 2013). Moreover, aphasia-friendly resources were reported to be a facilitator (Rose et al., 2012), for example, a book containing information about aphasia (Berens, Laney, Rose, & Howe, 2008).

Two projects involving improving access to outpatient health services for people with aphasia have also been reported in the literature (Parr, Pound, & Hewitt, 2006; Simmons-Mackie et al., 2007). In one of the projects, outpatient as well as inpatient service providers were trained to improve communication access to their own services for people with aphasia (Simmons-Mackie et al., 2007). Following the training, outpatient service providers reported more success in meeting goals than inpatient providers. In addition, the outpatient service providers reported benefits to their service for those with aphasia (Simmons-Mackie et al., 2007). This report provides support for making changes at the systems level by training service providers, however, the report did not indicate if the users with aphasia agreed with the health providers on the success of the changes. In another project reported in the literature, individuals with aphasia talked about their experiences with health and social services and then worked with the service providers to design a training program to improve communication access (Parr, Pound, & Hewitt, 2006). The report was a positive example of service providers working together with their clients, in order to identify service improvements. Additionally, this report highlighted that people with aphasia need to be able to access services that not only benefit themselves but those that also support their family and friends. Although these two projects were not designed to be rigorous investigations of the interventions, they highlight the importance of obtaining the perspectives of service providers as well as service users, including family members, when identifying barriers to and facilitators for service access.

### **Barriers to and facilitators for accessing outpatient speech-language therapy services for individuals with aphasia**

There are some barriers to and facilitators specifically for accessing outpatient speech-language therapy services in the literature. For example, limited rehabilitation services available post-stroke have been described previously, including reports where people with aphasia found that their aphasia level was either too low or too high to qualify for treatment when they did find manage to find services (Le Dorze et al., 2014). Family members reported a lack of information on community services or support groups from speech-language therapists, reporting that instead, their main source of information was through their peers with aphasia, highlighting the importance of networking (Kong, 2011). Organisations such as stroke groups were also reported to lack the financial resources to hire a speech-language therapist (Le Dorze et al., 2014).

From a speech-language therapist perspective in Australia, barriers were reported such as not enough one-to-one time for clients, and limited resources to provide a sufficient service (Verna, Davidson, & Rose, 2009). A lack of culturally relevant resources was also reported by speech-language therapists in Singapore (Guo, Togher, & Power, 2014). As also found in the literature pertaining to inpatient health services, people with aphasia reported that the discharge process made them feel abandoned, and without fully understanding why this had occurred (Hersh, 2009; Le Dorze et al., 2014). Some facilitators found included client satisfaction with their speech-language therapist, whether that related to the relationship they had with their therapist (Hersh, 2009), the therapists' expertise, or the client's progress in therapy (Le Dorze et al., 2014).

### **Barriers to and facilitators for accessing outpatient speech-language therapy services for family members of people with aphasia**

Given the substantial effect of aphasia on family members, it is important that their speech-language therapy needs and own goals for rehabilitation are considered (Grawburg, 2014; Howe et al., 2012). Family members report that speech-language therapists often have limited or no goals for them (Sherratt et al., 2011). As mentioned in several areas of the literature, family members also report not having access to enough information about aphasia and available services, as well as

struggling to access services; particularly if there was a long waiting list (Le Dorze, 2010). Good communication between the rehabilitation team, the person with aphasia, and their family members was reported to be a facilitator, in addition to respectful attitudes from professionals that helped family members to feel open about sharing their needs (Hallé, 2014). The opportunity to participate in communication partner training for family members was considered to be a significant facilitator, aiming to reduce communication breakdowns and helping them to communicate most effectively with the family member with aphasia (Blom Johansson, Carlsson, Östberg, & Sonnander, 2012).

### **Rationale for the current study**

In summary, the research studies to date have identified some barriers and facilitators that may influence the participation of individuals with aphasia in outpatient speech-language therapy services, as part of the larger aims of those studies. However, to date, no investigation has focused specifically on identifying barriers and facilitators that influence access to outpatient speech-language therapy services for adults with aphasia. In addition, investigations in this area have not included a focus on the barriers to and facilitators for accessing these services for family members of adults with aphasia. Research in this area is important at both the policy and clinical levels. The following sections outline the importance of the study in relation to international policy, national policy, and clinical practice.

#### **Importance in relation to international policy**

In order for people with aphasia to have optimal inclusion in society, interventions improving access to different domains of the environment should be explored and researched, including access to information and communication. The World Report on Disability stipulates it is essential to research the impact of environmental factors on disability and discover how best to measure it, while determining the strategies to overcome barriers of mainstream and specific services, within various contexts (World Health Organisation, 2011). As previously mentioned, this study will concentrate on the specific service of speech-language therapy in an outpatient setting, and will explore the impact of environmental factors in this setting

for people with aphasia, from the perspective of people with aphasia, their families, and service providers including speech-language therapists.

Establishing a 'culture of accessibility' must become an objective where the focus is on removing basic environmental barriers (World Health Organisation, 2011). However, research must not only concentrate on decreasing barriers, it is also equally important to increase facilitators in order to construct an optimum facilitative environment (Threats, 2007). An accessible environment will benefit a broader range of people, which in turn can help to achieve more support for change. As the World Report on Disability states, "Once the concept of accessibility has become ingrained and as more resources become available, it becomes easier to raise standards and attain a higher level of universal design" (World Health Organisation, 2011, p. 169).

It is essential for new investigations to add and strengthen the existing archive of disability research, which can then further inform disability policy and programmes, as well as determine where resources should be allocated (World Health Organisation, 2011). Research must also have the responsibility to ensure policy makers' understanding that access to health services is not only physical access (Worrall et al., 2005). While people with physical disabilities have a right to physical access (e.g., wheelchair ramp), people with communication disabilities have the right to 'communicative ramps' to facilitate communicative access (Kagan, 1998; Worrall, Rose, Howe, McKenna, & Hickson, 2007).

Environmental factors were included in the ICF (International Classification of Functioning, Disability and Health) to achieve a more fair society for people with disabilities (World Health Organisation, 2001). Research in this area is limited. "The political notion that disability is as much the result of environmental barriers as it is of health conditions or impairments must be transformed, first into a research agenda, and then into valid and reliable evidence. This evidence can bring genuine social change for persons with disabilities around the world" (World Health Organisation, 2001, p.243). The impact that environmental factors have on the lives of people with health conditions are diverse and complex, therefore future research is anticipated to show a better understanding of this interaction (World Health Organisation, 2001). With respect to communication disorders, there are also currently limited tools to measure the ICF's environmental factors in a reliable and valid manner (Threats, 2007). This study could add to research that addresses these issues. Taking into

account the above recommendations for further research, this study aims to add to the disability knowledge base in order to assist the future development of a well-established, uniform global service for people with aphasia.

### **Importance in relation to national policy**

In addition to international policies, this study is important in relation to national policies. First, all countries are expected to ensure that human rights and fundamental freedoms for all disabled people are on an equal basis with others, and without discrimination of any kind on the basis of disability, as outlined in the Convention on the Rights of Persons with Disabilities and Optional Protocol (United Nations, 2008). This is currently part of New Zealand law. All people with disabilities, including aphasia, have the right to full, effective participation and inclusion in society with equal opportunities, noting accessibility for all.

Another important policy that pertains to this research is the New Zealand Disability Strategy (Ministry of Health, 2001). This strategy provides a framework for ensuring that all government agencies consider disabled people in their decision-making processes. Some of the strategy objectives include fostering an aware and responsive public service, supporting quality living in the community for disabled people, and collecting and using relevant information about disabled people and disability issues in New Zealand (Ministry of Health, 2001). The specific goals and implications of this investigation will aim to be applicable to these broader strategy objectives.

The New Zealand Clinical Guidelines for Stroke Management (Stroke Foundation of New Zealand, 2010) is a third policy that is important to consider in relation to this study. These guidelines provide national recommendations referring to the organisation and protocols surrounding care before and after stroke. The guidelines state, “Environmental barriers facing those with aphasia should be addressed, such as through training communication partners, raising awareness of and educating about aphasia in order to reduce negative attitudes, and promoting access and inclusion by providing aphasia-friendly formats or other environmental adaptations” (Stroke Foundation of New Zealand, 2010, p.29). This recommendation is described as a ‘consensus-based recommendation’, meaning this should be a standard, and on-going advice.

As the study will take place and be specific to Christchurch, New Zealand, it is crucial that national policies pertaining to specific cultures also be considered. Both the He Korowai Oranga (Ministry of Health, 2002) and the 'Ala Mo'ui: Pathways to Pacific Health and Wellbeing 2010–2014 (Minister of Health and Minister of Pacific Island Affairs, 2010) are based upon joint values, which can be found in Maori, Pacifica, and disability culture. It includes the importance of working with iwi/hapu to identify and address their disability support needs.

Finally, the New Zealand Speech-Language Therapists' Association (NZSTA) is the national association for speech-language therapists in New Zealand. The NZSTA Scope of Practice (NZSTA, 2012) outlines the expectations required of practising speech-language therapists of the NZSTA, such as increasing “access and participation in various communication environments”, including health and community environments (NZSTA, 2012). Therefore this study aims to add to the professional knowledge base of speech-language therapists and related professionals.

### **Clinical importance of the study**

The study is important in relation to clinical practice. The definition of disability has transformed over the last twenty years; with it now being considered to be the outcome of the interaction between individuals and their environment (O'Day & Killeen, 2002). Research in the United States acknowledges that the environment plays a significant role in the wellbeing and health of people with disabilities, suggesting that agencies should assess the environmental factors that increase or decrease participation (Rimmer & Rowland, 2008).

This study will include the views of people with aphasia. It is important that research involves the perspectives of those with aphasia, because this can improve the service provided to them (Pound, Duchan, Penman, Hewitt, & Parr, 2007). In addition, available information and access to services is reported to be essential for a person to 'live successfully' with aphasia (Brown, Worrall, Davidson, & Howe, 2010). In a study examining communicative access to aphasia websites, people with aphasia did not agree with speech-language therapists on what constitutes an accessible website (Ghidella, Murray, Smart, McKenna, & Worrall, 2005). Therefore

it is important to include the person with aphasia for their expertise, without assuming what is best for this population. Family members such as significant others, and friends of those who have aphasia are also “valuable sources of information about the person’s communication disability and effective ways to communicate with him or her” (Blom Johansson, Carlsson, Östberg, & Sonnander, 2012; O’Halloran, Hickson, & Worrall, 2008). This study will include the perspectives of the respective family members or friends, who are frequent communication partners of the participants who have aphasia. Family members also have their own rehabilitation needs and goals that need to be addressed (Grawburg, 2014; Howe et al., 2012). Their perspective regarding accessing speech-language therapy services is therefore also important.

Lack of awareness of aphasia as a barrier to participation is not only reported by those with aphasia (Howe et al., 2004), but also service industry workers (Brown et al., 2006; Garcia, Barrette, & Laroche, 2000), therefore speech-language therapists are encouraged to educate and train service providers, including government agencies and private organisations (Kagan & LeBlanc, 2002; Togher, Hand, & Code, 1997), while encouraging and facilitating people with aphasia to become self-advocates (Brown et al., 2006). Such recommendations influence the ever-changing role of the speech-language therapist; “[it is] imperative that SLTs demonstrate strong leadership in supporting organisations and people with aphasia to identify and remove the barriers that impede the rights of people with aphasia to participate in the community” (Brown et al., 2006). Speech-language therapists are therefore encouraged to consider their role outside of being a rehabilitator. Speech-language therapists need to evaluate the distinct environmental factors impacting on their clients’ everyday community participation and take their experiences into consideration, planning socially oriented therapeutic goals accordingly (Brown et al., 2006; Brumfitt, 2006; Howe et al., 2004). As speech-language therapists have this responsibility, their perspective will also be included in this study. Community education and training could be provided in order to achieve increased awareness and an aphasia-friendly environment, as well as remind service providers of their obligation to be accessible to all their consumers (Worrall et al., 2005). However, more research is needed to identify what collaboration with service personnel will look like (Brown et al., 2006), therefore the study aims to include the perspective of



speech-language therapy outpatient employees, in addition to speech-language therapists.

Investigating access to outpatient speech-language therapy services should be relevant and appropriate while speech-language therapists and other related professionals are advocates for communicative access in the environment. They must have the responsibility for ensuring their own service is as 'aphasia friendly' as possible, especially if they expect to guide other services (Worrall et al., 2013). The findings from the study will be used to inform the development of more accessible speech-language therapy outpatient services for individuals with aphasia.

The findings from this study may also have a bearing on improving the communication accessibility of similar services such as other therapy outpatient services. Even communication barriers between healthcare services and those who do not have a communication disability have been reported (O'Halloran et al., 2008). Those individuals may have English as a second language, a different cultural background, and poor literacy or be of old age. Therefore the implications of this study could benefit a wider range of people with regards to communicative access (Kagan & LeBlanc, 2002; Worrall et al., 2007).

## **Research aims**

The current study, therefore has two aims:

1. To explore the barriers and facilitators that influence the access of adults with aphasia and their family members/friends to an outpatient speech-language therapy aphasia clinic from the perspectives of adult clients with aphasia, their family members/friends who accompany them to the clinic, and the fourth year speech-language therapy students involved in the clinic.
2. To identify a consensus of the most important barriers and facilitators that influence access to an outpatient speech-language therapy aphasia clinic by adults with aphasia and their family members/friends from the perspectives of adult clients with aphasia, their family members/friends who accompany them to the clinic, and the fourth year speech-language therapy students involved in the clinic.

## **Method**

### **Research design – modified Delphi technique**

A modified Delphi technique with two rounds was chosen to address the research aims. This iterative technique requires the participation of a panel of experts to come to a consensus regarding the research topic, following two or more rounds of research (Keeney, Hasson, & McKenna, 2011). The Delphi technique is an adaptable technique widely used by researchers, due to its ability to be flexible in either qualitative and quantitative research methods (Skulmoski, Hartman, & Krahn, 2007).

The classical Delphi technique involves presenting an open-ended questionnaire to a panel of experts in a first round to generate opinion in a specific field. The responses from the first round are then summarised and presented to the panel in subsequent rounds in order to gain consensus on the issue. Modifications to the classical Delphi technique are often made in certain fields such as health care practice research (Holloway, 2011). In this study, the technique was modified from the classical Delphi technique by using two rounds and conducting face-to-face interviews with the participants with aphasia for both rounds (Fletcher & Marchildon, 2014). Although the classical Delphi usually involves three rounds of research (Keeney et al., 2011), participants often prefer not to have to complete multiple questionnaires that are all similar during the research process and the outcomes may differ little with additional rounds of data collection (Linstone & Turoff, 1975). For the purposes of this study, two rounds were considered to be the most appropriate for the research timeframe and number of participants, avoiding unnecessary repetitions that may inconvenience the participants (Fletcher & Marchildon, 2014). In the first round, qualitative data was collected using open-ended questions that were administered during semi-structured interviews with the participants with aphasia and through written questionnaires with the family member/friend participants and student speech-language therapists. The second round involved summarising and organising data from the first round to present back to the participants, and collecting quantitative data through the use of Likert scale questionnaires. Responses from both rounds were kept anonymous.

### **Rationale for using modified Delphi technique**

The modified Delphi technique was used in this investigation for a number of reasons. First, this technique was chosen because of its purposeful participatory nature. Because all participants influenced the design of the round two questionnaires, and all participants' questionnaire responses had the same weight; each response was equally valued (O' Rourke et al., 2014). This method was also chosen, as it was appropriate for gaining collectively formed statements from participants where there is inadequate information on the research aims (Linstone & Turoff, 1975). Benefits for choosing the modified Delphi technique also included being able to uncover any underlying assumptions that lead to various opinions and judgements, as well as being able to educate stakeholders throughout the process about the diverse and complex sub-topics of the main research topic (Turoff, 1970).

Furthermore, the Delphi technique allows for participants to share their views without the influence of other experts being present (Fletcher & Marchildon, 2014), and provides a degree of anonymity among the participants (Keeney et al., 2011). The expert panel, made up of participants with aphasia, family members/friends, and student speech-language therapists, was able to contribute to this research without being required to meet altogether.

A qualitative research design underpinned by a constructivist research paradigm was chosen when gathering data for the first round. Qualitative research aims to comprehend the participants' experience from an insider's perspective, allowing them to "speak in their own voices rather than conform to the words and categories chosen for them by others" (O'Day & Killeen, 2002). In this way, qualitative research can expose realities that are often missed in quantitative approaches (O'Day & Killeen, 2002; Patton, 2002). Realities are made up of social and contextual constructs, meaning that various perspectives and realities exist in all settings and conditions. This includes the participants' experience of the daily reality, providing the type of knowledge and consequent recommendations that can encourage practical use immediately (O'Day & Killeen, 2002). In qualitative research, "the aim of research is not in uncovering a pre-existing truth, but in uncovering meaning: how people make sense of their lives, their experiences, and their world." (O'Day & Killeen, 2002, p.10).

Face-to-face semi-structured interviews were employed with the participants with aphasia during the first round. This type of interview involved a controlled

conversation between the researcher and informant, focusing on the same set of open-ended questions that were presented in the round one written questionnaires to the family member/friend participants and the student speech-language therapists (Minichiello, 1990). This approach also allowed for the questions from the first round to be presented in a multi-modal format based on recommendations from 'Supported Conversation for Adults with Aphasia' (SCA) (Kagan, 1998). The specific techniques utilised during the interviews to maximise the participants' understanding and language expression included the use of written key words and accompanying photos, in addition to spoken words, and the use of repetition and rephrasing of the questions. Face-to-face interviews were also beneficial in the initial round because the participants with aphasia had the opportunity to feel appreciated and therefore more likely to participate in future rounds (Keeney et al., 2011; Patton, 2002). In addition, interviews allowed the participants to share their experiences at their own pace.

In the first round, the family member/friend participants and student speech-language therapists completed written questionnaires consisting of the same provided to the participants with aphasia in their interviews. These participants could complete the questionnaires on their own time.

In the second round, the Delphi technique also allows participants to retract any responses from the first round, as they may have changed their minds or feel more comfortable expressing their true thoughts, whether this occurs upon further reflection, or increased willingness to contribute (de Meyrick, 2001). The core assumption of the Delphi technique is that group expert opinion is more reliable than using a single person's expert opinion (Helmer, 1966). This assumption is accepted by many healthcare industries (Holloway, 2011). The advantage of gaining consensus is that any views initially expressed only by one or few participants can be eliminated in subsequent rounds, allowing the final results to become further representative of the expert group (Keeney et al., 2011).

### **Limitations of the modified Delphi technique**

There are a number of limitations of the modified Delphi technique that researchers need to be cognizant of. First, researchers need to be aware of the impact of design flexibility on the validity of the research (Skulmoski et al., 2007);

many researchers do not realise how complex the Delphi can be until they utilise it (Keeney et al., 2011). This is an issue that required consideration in the current investigation as it utilised both qualitative and quantitative methods for the modified Delphi technique.

The design of the modified Delphi technique can also influence participants. Some participants never met the researcher while taking part in this study. Therefore, the willingness to stay accountable and continue taking part in subsequent rounds can affect the results, in addition to decreased incentive and motivation to take part without the encouragement of face-to-face contact (Keeney et al., 2011). If participants lose interest in the study or feel pressed for time, it can also result in quick completion of a questionnaire, leading to inaccurate representations of the participants' views, and therefore less accurate results overall (Fletcher & Marchildon, 2014).

It is important to note that although this method allows for a degree of anonymity among the participants, it is not absolute anonymity; therefore there is a risk of participants making guesses towards identifying other participants, or suspecting the person behind a specific response (Keeney et al., 2011).

## **Participants**

The individuals who participate in a study involving the Delphi technique need to be a panel of experts who have a wealth of relevant information with regards to the research topic (Keeney et al., 2011). For the purposes of this study, the three groups of participants who were considered to have this expertise were adults with aphasia, their family members or friends who accompanied them to the clinic, and the student speech-language therapists involved in the clinic. Each participant group had their own inclusion criteria. The inclusion criteria for the participants with aphasia were:

- adult with aphasia secondary to stroke who was 18 years of age or older; who had attended the University of Canterbury Speech-Language Therapy Aphasia Clinic in 2014.

The inclusion criteria for the family member/friend participants were:

- family member/significant other/friend/paid carer of a participant with aphasia who was 18 years of age or older;
- who had accompanied the participant with aphasia to the University of Canterbury Speech-language Therapy Aphasia Clinic in 2014 on at least one occasion; and
- could complete a written questionnaire in English.

The inclusion criteria for the student speech-language therapists were:

- fourth year University of Canterbury Bachelor's of Speech-Language Pathology student who was 18 years of age or older; and
- who had completed a clinical rotation in the University of Canterbury Speech-language Therapy Aphasia Clinic in 2014.

Exclusionary criteria included participants with aphasia who could not participate in an interview in English facilitated by supportive conversation techniques for adults with aphasia (Kagan, 1998) and any participant who was not able to complete both rounds of the study.

### **Recruitment**

The administrator of the University of Canterbury speech-language therapy clinic sent potential participants who met the inclusion criteria a research information packet inviting them to contact the researcher directly if they were interested in participating in the study. The packet included an invitation letter, research information sheet, and consent forms (see Appendices K-O). Potential participants with aphasia and their family members/friends received a packet in the mail, while student speech-language therapists received this packet via email. For those with aphasia, the packet included information based on the principles of modified written information for people with aphasia (e.g., pictures to aid understanding, large font on a white background, simplified language and less text on a page) (Rose et al., 2011).

### Participant demographic information

In total, 36 potential participants were approached; 12 student speech-language therapists, 12 adults with aphasia, and 12 family members/friends who the person with aphasia would identify as their accompanying person to the clinic. Ten adults with aphasia and their family members/friends responded with initial interest and consent, with individual with aphasia and family member declining before the first round due to health issues. Therefore, nine adults with aphasia, and nine family members/friends completed both rounds. Five student speech-language therapists responded with initial interest and consent, however, two student speech-language therapists did not return the questionnaires during the first round of data collection. Another student speech-language therapist did not respond during the second round, leaving two student speech-language therapists who completed both rounds. In total, 20 participants completed both rounds (Tables 1, 2, and 3).

**Table 1: Characteristics of the participants with aphasia**

Characteristic	Number of participants in Rounds 1 and 2 (N=9)
Gender	
Female	2
Male	7
Age (range = 55-76 years, mean +/- SD = 65.5 +/- 8)	
≤ 64	4
≥ 65	5
Aphasia severity (based on WAB-R* AQ** or WAB-R* Bedside Language Score)	
Mild	3
Moderate	1
Severe	3
Very severe	2
Aphasia type (based on WAB-R or WAB-R Bedside classification criteria)	
Anomic	4

Conduction	2
Broca's	2
Global	1
Number of strokes	
1 Left cerebrovascular accident (CVA)	7
2 Left CVA	2
Premorbid handedness	
Left	1
Right	8
Time post-onset of aphasia (months) (range = 11 – 101 months, mean +/- SD = 39.5 +/- 30.8)	
0 -12	1
12 > 60	6
≥ 60	2
Living situation	
Living with 1 adult family member in own home	8
Living with 2 adult family members in own home	1
First language	
English	9
Ethnicity	
NZ European	9
Highest education level	
Completed some high school	2
Completed high school	3
Completed tertiary certificate or diploma/undergraduate degree	3
Other	1
Work situation	
Working at time of first stroke and at time of interview	1
Working at time of first stroke, but not at time of interview	6
Not working at time of first stroke and at time of interview	2
Transport to clinic	
Participant with aphasia drives	2
Family member/friend participant drives	6
Bus	1



Mobility	
Sometimes uses wheelchair when travelling to clinic	2
Always uses walking stick when travelling to clinic	2
Sometimes uses walking stick when travelling to clinic	1
No mobility aids used when travelling to clinic	6

\* Western Aphasia Battery - Revised

\*\* Aphasia Quotient

**Table 2: Characteristics of the family member/friend participants**

Characteristic	Number of participants in Rounds 1 and 2 (N=9)
Gender	
Female	8
Male	1
Age (range = 56 – 76 years, mean +/- SD = 67.1 +/- 6.6 )	
≤ 64	4
≥ 65	5
Relationship to participant with aphasia attending clinic	
Spouse/Partner	8
Friend	1
Length of time known the participant with aphasia (years)	
0-10	1
≥ 10	8
First Language	
English	9
Ethnicity	
NZ European	9
Highest education level	
Completed some high school	3
Completed high school	2
Completed tertiary certificate or diploma/undergraduate degree	3
Other	1

Frequency of accompanying the participant with aphasia to the clinic	
Almost every time	1
Every time	8
Transport to clinic	
Family member/friend participant drives	6
Participant with aphasia drives	2
Bus	1
Mobility	
No mobility aids used when travelling to clinic	9

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**Table 3: Characteristics of the student speech-language therapy participants**

Characteristic	Number of participants in Round 2 (N=2)
Gender	
Female	2
Age (years)	
18-29	2
Ethnicity	
NZ European	1
NZ European/Maori	1
Number of clients seen in individual sessions	
1	1
2	1
Number of clients seen in group sessions	
7	1
8	1
Previous student experience working with people with aphasia	
None	1

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## University clinic context

The UC aphasia clinic is an outpatient speech-language therapy service for adults with aphasia and their families/friends who live in the community. Clients may refer themselves to the clinic or may be referred by community speech-language therapists. The clinic includes two different clinical cohorts, each consisting of approximately four to six adults with aphasia and their family members/friends. There were 12 clients in 2014. In 2014, some of the clients and their family members/friends participated in a month long intensive programme, which consisted of two-hour groups twice a week and one-hour individual sessions twice a week. The rest of the clients in addition to the clients described above attended the clinic during the two twelve week university semesters. During each semester, the clients with aphasia were seen once a week for a two-hour group session and some clients were additionally seen once a week for a one-hour individual session. At the time of the investigation, group sessions were held in a large individual one-storey classroom building, one of 57 individual buildings located in a 'temporary' campus village built at the university. Individual therapy sessions were held in buildings within the 'temporary' campus village, in clinic rooms within the university's Department of Communication Disorders, or in the client's home. This was built to enable further space for learning following damage to the teaching facilities as a result of the Christchurch earthquakes. There was no cost for any of the sessions provided by the university, apart from a gold coin donation per group session to cover the cost of morning teas. In addition to giving this money, some family members brought food items they had baked. Students from the university's four year Bachelor's of Speech-Language Pathology and two year Master's of Speech-Language Pathology programmes were assigned to the clinic to complete supervised clinical rotations as part of their degree requirements. Some clients had one student allocated to them, while other clients had two. While there was one clinic co-ordinator who managed the clinic, additional clinical educators also supervised the students during the intensive placement at the university clinic. During individual sessions, family

members/friends usually stayed with the clients with aphasia and participated in the activities when appropriate. During group sessions, family members/friends were considered to be part of the group and could participate in the group activities.

University staff, students, and the aphasia clinic clients were required to pay for parking at the temporary campus village a rate of \$7.50 an hour at the time of investigation. The car park at this site has one disabled car park. The Department of Communication Disorders has a number of reserved car parks for clients in their allocated car park. These car parks are free of charge.

## **Data collection**

### **Round one – Data collection**

After gaining initial consent, interviews were arranged at a time that suited the participant with aphasia. All participants with aphasia chose to have their spouse or friend present at the interview, and all chose to have their interviews conducted in their homes. The informed consent process was a continuous one, where the participants' willingness to remain involved was periodically checked (Kagan & Kimelman, 1995; Lloyd, Gatherer, & Kalsy, 2006; Penn, Frankel, Watermeyer, & Muller, 2008). In addition, the researcher monitored any nonverbal signals indicating discomfort or stress during the informed consent process, and during any subsequent interactions with the participant (Lloyd et al., 2006). Before the interview, participants were informed about the purpose of the research, and the structure of the interview.

A topic guide based on the open-ended written questions for round one was used during the semi-structured interviews. Please refer to Appendix E for the topic guide, which contained questions about perceived barriers and facilitators for access to the university clinic. The participant with aphasia was offered a choice of question formats; text only or supported by pictures. This choice was provided in case they were offended or did not appreciate some of the proposed generic aphasia-friendly design features (Jayes & Palmer, 2014). Facilitative communication strategies recommended by Kagan (1998) were employed, such as the use of visual material. Photos of the university clinic and relevant items were kept in an additional visual resource folder to assist with the interviews.

The interviews with the participants with aphasia were video-recorded, to capture any essential non-verbal communication used during their interactions with the researcher. In addition, interviews were audio recorded using a digital voice recorder at the same time, to provide back-up data if the video recording failed. A reflective journal was also kept to record the researcher's reflections about each research session.

Family member/friend participants and student speech-language therapy participants completed an online or paper version of the questionnaire on their own, containing the same questions provided in the interviews for the participants with aphasia. These were returned to the researcher by mail or email. Email reminders were distributed to any participants who had outstanding questionnaires to return. Demographic information was obtained from the three participant groups via the administration of demographics information forms, and for those with aphasia, completion of a consent form to allow the researcher to gain further information about the participant from client files at the university.

### **Round two – data collection**

The codes from round one were used to develop the list of barriers to access and facilitators for access in the questionnaire for the second round (Appendix J). Any identifying information in the questionnaire was removed to retain anonymity of the participants. The questionnaire began with a list of facilitators for access and finished with the list of barriers to access to the university aphasia clinic, and participants were asked to indicate to what extent they agreed or disagreed with each statement being an important barrier or facilitator. The questionnaire format was presented as a five-point Likert scale, with the following responses: "strongly disagree", "disagree", "neither agree nor disagree", "agree", and "strongly agree".

Each group of participants completed the same questionnaire, whether they completed this in person with the researcher present, or on their own. Some family/friend participants and the student speech-language therapists were able to respond in their own time, in the comfort of their chosen location, without the need for face-to-face meetings. Responses were emailed back to the researcher, and after two weeks, any outstanding respondents were reminded with a follow up email.

For round two, participants with aphasia were seen for another face-to-face meeting in their homes using supported conversation techniques in order to help them to complete the questionnaire. The questionnaire for participants with aphasia was adapted to be as 'aphasia-friendly' as possible with guidance from the research supervisors. It included features such as larger text, bolded words, and photos and symbols to support the person with aphasia's understanding (Appendix I). In addition, the researcher used communication strategies such as repetition and rephrasing of questions as required during the completion of the questionnaire.

## **Analysis**

### **Round one – Analysis**

The researcher examined the video-recordings from round one, immersing herself in the data. The video-recordings were then transcribed verbatim based on conventions proposed by Poland (1995). All participants with aphasia chose to have a family member/friend participant present during the round one interviews. All family member comments on the research topic during these round one interviews were also transcribed and included in the final analysis as qualitative data from the family member/friend participants. The transcriptions and all the data from the open-ended written questionnaires were then analysed using qualitative content analysis (Graneheim & Lundman, 2004) in order to identify the specific barriers and facilitators, and categories of barriers and facilitators for accessing the university aphasia clinic. Qualitative content analysis was the chosen analysis technique for round one because it is "used to refer to any qualitative data reduction and sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meanings" (Patton, 2002). The first stage of analysis involved highlighting content areas, beginning with content in the transcripts that was not related to the main research question (e.g., "I'm just going to shut that curtain"). This was marked to show it would not be included as a unit of analysis and would not be further analysed. The remaining content was organised into two groups: perceived barriers to access and perceived facilitators for access. Meaning units were then identified and condensed and potential codes were then assigned. Once potential codes were assigned to all the identified meaning units, codes were grouped together to form categories. The final categories of codes were summarised and

simplified into 'aphasia-friendly' language as much as possible with the guidance and assistance of the researcher's supervisors.

### **Round two – Analysis**

The questionnaire responses were analysed quantitatively by identifying the frequency of responses for 'agree' and 'strongly agree' to determine the number of barriers and the number of facilitators that had reached consensus. Any multiple responses or incomplete responses for individual items were not counted. For the purposes of this research, consensus was considered to be 51% or more of the participants responding with either "agree" or "strongly agree", as suggested by Loughlin and Moore (1979). If a statement reached this threshold, it would be considered an important barrier to or facilitator for accessing the university aphasia clinic. These items were then ranked from the most important barrier/facilitator to the least important, from the three groups of participants altogether, in addition to the perceptions of each individual participant group. This was done by ranking responses that achieved a consensus rate of 100%, down to responses that achieved a minimum of 51% consensus.

### **Rigour and reflexivity**

Rigour is the way in which researchers attempt to increase the quality of their data, by ensuring that it is credible, transferable, dependable and confirmable where possible (Liamputtong, 2013; Patton, 2002). This research project followed some strategies as recommended by Patton (2002) to increase the reliability of data collected in both rounds:

- Triangulation of data sources was one of the strategies used to enhance the rigour of the overall study. Multiple perspectives were acquired from three different groups of participants to help achieve triangulation. Triangulation is a technique that can also help increase confirmability to reduce the researcher bias (Patton, 2002).

- Prolonged engagement with participants with aphasia and the family member participants in the field increased the rigour of the study by helping to build rapport and a trusting relationship (Liamputtong, 2013). This was achieved by having more than one meeting with the participants with aphasia and their family members/friends, each meeting lasting between an hour and three hours in the first round, and half an hour to three hours in the second round.
- A research diary was kept, detailing field notes from interviewing, as well as the description of the setting, people, and location. Any social contexts were additionally described. The diary was also used to reflect critically on the researcher's biases, and her self and reality constructs in relation to the study, such as descriptions of thought processes, in order to demonstrate reflexivity (Liamputtong, 2013; Rodgers & Cowles, 1993).

### **Ethical considerations**

The University of Canterbury Human Ethics Committee approved this study in November 2014 (see Appendix A).



## Results

### Overview

The analysis of the data revealed that participants with aphasia, family members/friends, and student speech-language therapy participants perceived various barriers to and facilitators for accessing the university aphasia clinic. The results are presented in two parts reflecting the first and second rounds of the study. First, the barriers to and facilitators for access to the university aphasia clinic are presented from round one, followed by the consensus regarding the most important barriers and facilitators identified by participants in round two. Participant quotations are provided to illustrate the results. Deidentified participant codes are provided after quotes to preserve anonymity (i.e., participants with 'P' in front of the number refer to participants with aphasia such as P2. Participants with 'F' in front of the number refer to family members/friend participants such as F6, and participants with 'S' in front of the number refer to student speech-language therapy participants such as S1).

### Results from round one - Barriers

Qualitative analysis of the semi-structured interviews and questionnaires with open-ended questions in round one revealed 23 barriers to access, grouped within eight categories: Information about the clinic, logistics, people at the clinic, communication during the sessions, therapy activities, location and physical features, services for family, and miscellaneous (Table 4). Examples of specific barriers within each of these categories are provided in the sections below.

Table 4. Barriers to accessing the university aphasia clinic as identified by participants with aphasia, their family members/friends, and student speech-language therapists.

Category	Code
Information about the clinic	Hard to find out about the clinic

Logistics	Sometimes there are not enough students
	Group members and students change each semester
	Not enough group spots for people with aphasia
	Hard to fit around clinic schedule
	Long breaks between terms
	Getting ready for a home visit is sometimes difficult
People at the clinic	Hard to remember the students
	Students are not experienced enough
Communication during the sessions	Not enough time to speak
	Sometimes too noisy in the group
	Hard to read the whiteboard
	Sometimes students speak too fast or in long sentences
	Sometimes students did not explain activities clearly
Therapy activities	Same activities every week
	Some sensitive topics
	End of year party group too big
Location and physical features	Hard to park
	Hard to read signs and find way around the clinic
	Clinic door locks
Services for family	No place for family to meet
Miscellaneous	The clinic is more for the students

### **Information about the clinic**

All participant groups commented that it would be difficult for others to find out about the university clinic. Many participants discovered the clinic through their local aphasia club, with the university clinic approaching the club first: *"... I didn't find out until ... somebody said ... I go to aphasia ... group... I heard there....got my name down, and she [the clinic coordinator] rung me. ... no it was difficult [to find out about the service]...how do you know? [about it?]"* (P1). Representatives from all groups of participants also reported that discovering the university clinic through word of mouth appeared to be the primary source of information: *"Yes, it just seems to be hit and miss ... some know about it [the university clinic], some don't ... often they [people with aphasia and their families] do not know where to get that help"* (F1).

### **Logistics**

Issues with the logistics of the university aphasia clinic were considered to be barriers to access for many participants. For example, participants mentioned there were limited group openings for people with aphasia at the university aphasia clinic. The group members and students also changed each semester. As a result, some participants reported missing the friends they had made in previous groups: *"...miss good friends [in previous groups]..."* (P1).

In addition, participants reported missing the students once they completed their placements: *"... then they were done and that was it and that was lovely ... then we find another /wpst/ [group of students], so that's good, but ... trouble is, we've [they've] just been ... too good ... they've just been too lovely, all of this, that's the hard [part] ..."* (P2). Occasionally not having enough students for the clinic was identified as a barrier,

Issues with time aspects of the university aphasia clinic were raised by individuals from of all participant groups. For example, the university clinic groups finishing each semester, rather than continuing on during semester breaks as a continuous service, was identified as a barrier. The clinic ending for several months at the end of the academic year made it difficult for some participants with aphasia

who tried to receive services from other locations during the break. Another barrier raised with regards to time was difficulties with scheduling, such as schedule changes between semesters, and the lack of flexibility for the clinic group day and time: "... *they've [the university] only got a certain time in the day they can devote to this course ...*" (F6). Students' schedules were also raised as an issue: "... *she [the student] was trying to work around what time she had available and what we had available ... and it just didn't work time wise.*" (F7). In addition, some family members/friend participants found it difficult to accommodate the clinic schedule when they were working: "...*often have to swap my hours so I am able to go with [P8's name]...*" (F8).

### **People at the clinic**

The only barriers relating to people identified by participants in this round concerned the students involved in the clinic. For example, some participants discussed the experience level of the students, and whether they would have the appropriate expertise to help the clients of the aphasia clinic. In addition, many participants found it difficult to recall the students they worked with during the interviews, with some participants saying the group CO is the only facilitator from the clinic they remembered well: "*She's [the Group CO] the only one I remember...*" (P1).

### **Communication during the sessions**

Not having enough time for the person with aphasia to say all they wanted to in the group was identified as a barrier, as was occasional noise in the group,

Difficulties with reading the whiteboard were identified as a barrier, such as writing that was too small, or words that were placed too close together. Some barriers were found with regards to the communication of the students, such as the students not explaining activities clearly, or students speaking too fast or in long sentences.

### **Therapy activities**

A few barriers were found with regards to therapy activities. For example, the routine of the group session schedule was identified as a barrier with some participants feeling was too repetitive and suggesting that an increased variety of activities would be more interesting. At the end of year party, the two aphasia groups from the university clinic came together to meet. Some participants felt this may have been less beneficial for the individuals with aphasia: “... *but probably harder for the aphasia people.... probably ... the bigger numbers.... they just tend to be really quiet.*” (F9).

### **Location and physical features**

Almost all participants identified barriers related to parking at the university clinic location. These barriers included difficulties finding a car park space and not having enough disability car parks available. Further barriers identified included the cost of parking and worrying about the parking meter running out before the clinic session finished.

The signage around the university clinic was identified as a barrier, with some participants reporting that there was inadequate signage to indicate the specific clinic room. Another barrier found under this category included participants finding that using the restrooms could be a problem, as someone had to open the automatically locking clinic door from the inside to allow a participant to return to the clinic room.

### **Services for family**

It was reported that occasionally, some family members found it difficult to locate a place to go on their own with other family members if they wanted to spend time together during the aphasia group.

### **Miscellaneous**

This category included miscellaneous barriers that did not fit within any of the other categories. For example, some participants shared their opinions on the perceived purpose of the university clinic, with one individual indicating that the

university clinic aimed to primarily teach the students, with rehabilitating the clients as a secondary aim: *“I ... feel that the whole thing is ... for the students and in a way it’s not for [P8’s name]... I mean it is for [P8’s name] but it’s more for the students, so we should just really go with the flow with whatever they do ... that’s how I feel this clinic is for...”* (F8). Another miscellaneous barrier for access included some participants being unable to eat some of the morning tea items due to a restricted diet.

## Results from round one - Facilitators

Analysis of the round one data revealed 37 facilitators for access (Table 5). These facilitators fell within nine categories: information about the clinic, referral to the clinic, logistics, people at the clinic, communication during the sessions, therapy activities, location and physical features, services for family, and miscellaneous. Examples of facilitators within each of these categories are provided in the following sections.

Table 5: Facilitators for access to the university aphasia clinic as identified by participants with aphasia, their family members/friends, and student speech-language therapists.

Category	Code
Information about the clinic	More advertising about the clinic
Referral to the clinic	Referral from hospital/community
Logistics	Small group size
	Breaking into small groups
	One on one time with the students
	Staying with the same student over the semester
	Having dates for the clinic ahead of time
	Students were flexible with schedules

	Two sessions a week and good length and pace of session
People at the clinic	<p>Meeting other people with aphasia and their families (e.g. friendships, support)</p> <p>People having a similar level of aphasia</p> <p>[Name of clinic co-ordinator], the clinic co-ordinator is friendly and understanding</p> <p>Students were helpful and friendly</p> <p>Knowing people at the group</p> <p>Having their family/friend come with them to the clinic</p>
Communication during the sessions	Lots of chances to talk
Therapy activities	<p>Lots of different stimulating activities</p> <p>Lots of everyday activities (e.g. using money, conversations)</p> <p>Activities to do at home</p> <p>Routine each week</p> <p>Therapy goals were what the person with aphasia wanted</p> <p>Pictures and written info helps clients understand the activities</p> <p>Meeting others at end of year party</p>
Location and physical features	<p>Choice of meeting at home or clinic (e.g. first visit and other visits)</p> <p>Clinic is in central location in Christchurch</p> <p>Clinic room with kitchen</p> <p>Toilets available beside the clinic</p>

	Parking at [name of speech-language therapy department site] (e.g. was convenient)
	Parking card for the car (for parking at [name of main aphasia clinic site])
	Signs
	Family sitting beside the other people with aphasia sometimes
Services for family	Family can watch the therapy Family group as well as aphasia group
Miscellaneous	Having the chance to help the students Clinic is safe and friendly Survey and report at the end Extra things e.g. clipboards, coat hooks

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### **Information about the clinic**

All participant groups commented on the possibility of the clinic being advertised more, such as listings on the internet, and notices in relevant public health areas: “...*if they tried to [spread word of the clinic] in the ... doctor’s rooms ... that’s somewhere ... you are desperate to find something ...*” (P1). Further suggestions included networking opportunities to increase awareness of the university clinic: “... *build relationships with other organisations to advertise the group more broadly in the community*” (S2).

### **Logistics**

The person with aphasia’s individual time with the student was identified as a facilitator for access to the clinic. Having a smaller group size was identified as a facilitator. The number of participants in the group was also suggested to be appropriate for those with aphasia: “... *suited me that there was either the three or four people there [with aphasia] ...*” (P6).



Having a shorter break from the aphasia clinic between the end of the year and the beginning of the new semester was identified as a facilitator. As such, having the session schedule for the semester ahead was identified as a facilitator. In addition, some participants did find that the students were flexible with their schedules to meet theirs, and noted this as a facilitator. Other facilitators were identified with regards to time, such as the frequency of sessions, and sessions running at a suitable pace, with sessions starting and finishing on time.

### **People at the clinic**

Many participants commented on the benefit of meeting other people with aphasia and their families, and therefore finding others in the same situation as them. In addition, family members outlined the benefits of an unofficial family support group, as a result of meeting other family members of people with aphasia: “...*the carers went and did something different outside. ... we went for a walk ...when you see people with the same situation, and the carers having the same questions and the same discussions ...takes the fear away from it from a carer’s perspective ...we were all in that same sort of situation. ...that was really, really reassuring*” (F6).

Some participants spoke of the opportunity to measure their own experience against others’ situations: “... *and being amongst people that are similar ... I can achieve this where that other person can’t, but he can achieve something that I can’t. ... seeing that .... gave [P6’s name] ... confidence ... you realise that ... people are ... worse off than yourself ...*” (F6). Many participants also talked about the opportunity to build true and meaningful relationships, and feeling like they could be themselves: “... *everyone comes with who they are...*” (P1). Participants also highlighted the importance of support and acceptance from other group members having an impact on therapy: “*Everyone’s the same*” (P6). An opportunity to meet new group members in a new semester was considered a positive change to some participants. It was also reported that networking and receiving advice from other families allowed participants to explore more options, such as extracurricular activities they had not originally considered.

In addition, it was reported that it would be more helpful if group members were matched with a similar level of aphasia. Some participants felt that seeing the same group of people every week helped. Several participants also knew each other

from local aphasia groups, and felt that seeing a familiar face at the university clinic helped: *“I think the big thing is that we knew ... the people involved ...”* (F9).

Student speech-language therapy participants identified that having a family member/friend accompany the person with aphasia to the clinic was a significant facilitator, as this meant another familiar face existed in a new environment. In addition, most family members/friends assisted with the transport between the home and the university clinic.

Another facilitator frequently mentioned by participants was in relation to the presence of the group co-ordinator (CO). Many participants felt the group CO was welcoming, *“... [Group CO name] is very ... hospitable and ... makes everybody feel welcome and ... it’s fantastic”* (P1), understanding, and fulfilled her role well. Comments were also made with regards to the group CO’s level of maturity having an influence: *“... she is comfortable in her own skin ... she is forthcoming, it’s good that she’s there”* (P1).

In terms of other people in the group, participants commented on the positive aspects of the students’ role at the university clinic, such as their patience, friendliness, competence, and creativity. It also helped some participants having the same student throughout the term, acting as an advocate. Some participants felt that simply being in the presence of the students was beneficial: *“... it was nice to be in ... amongst young people ...and that is stimulating for [P6’s name] ... being in amongst young people ... it’s lovely ... I did feel that ... was very good”* (F6).

### **Communication during the sessions**

Many participants felt that there were plenty of opportunities for people with aphasia to communicate and contribute to the group, which helped them to feel valued.

### **Therapy activities**

Most participants identified that the activities involved in the university clinic were a significant facilitator, such as having a great variety of well-organised, interesting, relevant, social, and functional activities. Topics of conversation were seen as relevant, familiar, and interesting without being too controversial: *“Having*

*themes and topics that were universally interesting to the group, as well as topics that allowed them to talk personally, were highly motivating” (S1).*

The morning tea activity was identified frequently as a facilitator for the clinic. Other motivating activities took shape in the form of role plays such as acting out a court case, which often allowed opportunities for laughter

Focusing on activities of daily living, such as money handling and everyday conversations, was identified by participants as a facilitator: *“Functional activities that simulated real life activities (such as ordering coffees or choosing from a menu and handling cash) were motivating, helpful and fun for clients” (S1).* Other identified facilitators included holistic and person centred activities, flexibility in arranging activities, being given activities to do at home, and a suggestion for extra activities that encouraged group participants to get to know each other better.

A facilitator noted by representatives of all participant groups was that there was a person-centred approach to the clinic; therapy goals were what the person with aphasia wanted: *“... the girls looking after me for the phone and the, um, computer. I think that’s quite good really, very good, very good ... those are the things I had trouble with ...” (P6).*

Some participants identified the adaptations to activities in the university clinic as a facilitator, such as using visuals and written information to help people with aphasia understand the activities and increase their participation. Some participants felt that having a consistent, predictable session schedule each week was helpful.

At the end of year party, the two aphasia groups from the university clinic came together to meet. Some participants felt this was an ideal way to finish the end of each therapy term with the opportunity to network.

### **Location and physical features**

The increased accessibility of the clinic being in a central location in the city was identified as a facilitator. The clinic room with the kitchen was also identified as a facilitator.

Having the option to meet individually for the first time at the client’s home or at the university clinic was identified as a facilitator with several benefits. For example, the first visit to the home enabled the clients to gain information early on about the clinic, allowing them to know what to expect, and become familiar with the

student/s working with them. Participants reported that they would feel more relaxed at the clinic having a familiar face present. In addition, having the initial visit at home was found to be useful because clients felt more comfortable and did not have to leave home to navigate a new place.

Some participants suggested potential facilitators for improving the parking situation at [name of main aphasia clinic site], such as a parking card, which could be left on the car dashboard to show they were exempt from paying the parking meter. Advice from the group CO on where to park for free near the university was also identified as a facilitator. Parking at [name of speech-language therapy department site], where some individual sessions were held during the course of the university aphasia clinic, was identified as a facilitator due to its' convenience.

The colour-coded signage at [name of main aphasia clinic site] was identified as a facilitator, with some participants finding they were able to navigate through the university easily. Participants also found the restrooms situated immediately beside the clinic room to be a facilitator.

In addition, family member participants noted that the positioning of people with aphasia next to less familiar group members, such as family members of other people with aphasia in the clinic room was a facilitator. It was reported that this helped participants with aphasia to rely less on the assistance of their family member/friend.

### **Services for family**

A few participants identified that family members observing the therapy sessions was a benefit: "... *I learn a lot too ... just by seeing what she's [Group CO] saying to them [the students] and I think oh yeah true you could see that now ...*" (F3). Several participants felt an additional service for family members would be a facilitator, such as having a carer's group and aphasia group happening simultaneously, or having more options available for family members: "*Actually it would be nice to have a carer's group ... if there's any chance of a carer's group maybe, of all of them [carers of those with aphasia attending the clinic], you know, ... at the aphasia clinic that'd be good*" (F8).

## Miscellaneous

There were four facilitators that fell within the miscellaneous category. First, several participants commented on enjoying the opportunity to volunteer to help the students for their studies, and felt that the learning process was mutual between students and clients. The university clinic was also described frequently as a safe, relaxed, friendly, non-threatening environment by many participants. A third facilitator involved the use of a survey and report at the end of the semester to help in measuring outcomes. Finally, miscellaneous facilitators for access included participants suggesting extra physical objects that might help the clinic; such as clipboards and coat hooks.

## Results from round two – Most important barriers

Only two of the 23 barriers to access identified in round one were identified as being important by all three participant groups, with both achieving a consensus of 75%. This is shown in Table 6. The overall consensus for barriers to access in round two is shown graphically in figure A. The proportions for each participant group response is represented, with any overall response that crosses the line at 51% considered to have achieved consensus. Individual responses of each participant were weighted equally, giving the participants with aphasia group and family members/friends group up to 45% each of the total percentage of responses, and the student speech-language therapy group up to 10% of the total percentage of responses.

Table 6: Important barriers to access to the university aphasia clinic, as identified by all participants.

Ranking	Barrier
1	Hard to find out about the clinic
2	Not enough group spots for people with aphasia

Some important barriers were identified by a majority of participants within one or two groups, but not across all groups, as shown in Table 7. Of the 23 barriers to access identified in round one, four were considered to be important only by a majority of the participants with aphasia, two were considered to be important only by a majority of the family members/friend participants, and nine were considered to be important only by a majority of the student speech-language therapists. The barriers, 'sometimes students do not explain activities clearly' and 'it is hard to park' were only considered to be important by a majority of the participants with aphasia and the student speech-language therapy participants.

Table 7: Important barriers to access to the university aphasia clinic, as identified by each participant group.

Barrier	PWA	FM	SSLT
Hard to find out about the clinic	✓	✓	✓
Hard to remember the students			✓
Group members and students change each semester			✓
Not enough group spots for people with aphasia	✓	✓	✓
Hard to read the board			✓
Sometimes students speak too fast or in long sentences			✓
Sometimes students do not explain activities clearly	✓		✓
Hard to park	✓		✓
Hard to read signs and find way around the clinic			✓

### Results from round two – Most important facilitators

Of the 37 facilitators for access identified in round one, 36 were considered important across participant groups (Table 8), with three facilitators achieving a consensus of 100%. Only one facilitator (i.e., 'Extra things e.g. clipboards, coat hooks') did not achieve at least 51% consensus. The overall consensus for facilitators for access in round two is shown graphically in figure B.

Table 8: Important facilitators for access to the university aphasia clinic, as identified by all participants.

Ranking	Statement
1	[Name of clinic co-ordinator], the clinic co-ordinator, is friendly and understanding
2	Lots of chances to talk
3	Family group as well as aphasia group
4	Students are helpful and friendly
5	One on one time with the students
6	Staying with the same student over the semester
7	Lots of different stimulating activities
8	Lots of everyday activities (e.g. using money, conversations)
9	Activities to do at home
10	Therapy goals are what the person with aphasia wants
11	Pictures and written information helps clients understand the activities
12	Family can watch the therapy
13	Parking at [name of main aphasia clinic site] (e.g. parking card for the car would help)
14	Having the chance to help the students
15	Clinic is safe and friendly
16	Referral from hospital/community
17	Meeting other people with aphasia and their families (e.g. friendships, support)
18	Knowing people at the group
19	Having their family/friend come with them to the clinic
20	Small group size

21	Breaking into small groups
22	Having dates for the clinic ahead of time
23	Students are flexible with schedules
24	Signs
25	People having a similar level of aphasia
26	Toilets available beside the clinic
27	Family sitting beside other people with aphasia sometimes
28	Survey and report at the end
29	More advertising about the clinic
30	Meeting others at end of year party
31	Choice of meeting at home or clinic (e.g. first visit and other visits)
32	Clinic is in central location in Christchurch
33	Routine each week
34	Clinic room with kitchen
35	2 sessions/week and good length and pace of session
36	Parking at [name of speech-language therapy department site] (e.g. was convenient)

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Of the 37 facilitators to access identified in round one, 34 were considered important by the participants with aphasia, 36 were considered important by the family members/friend participants, and 24 were considered important by the student speech-language therapists (Table 9). Eleven facilitators were considered important by participants with aphasia and family members/friend participants, but not by student speech-language therapy participants.



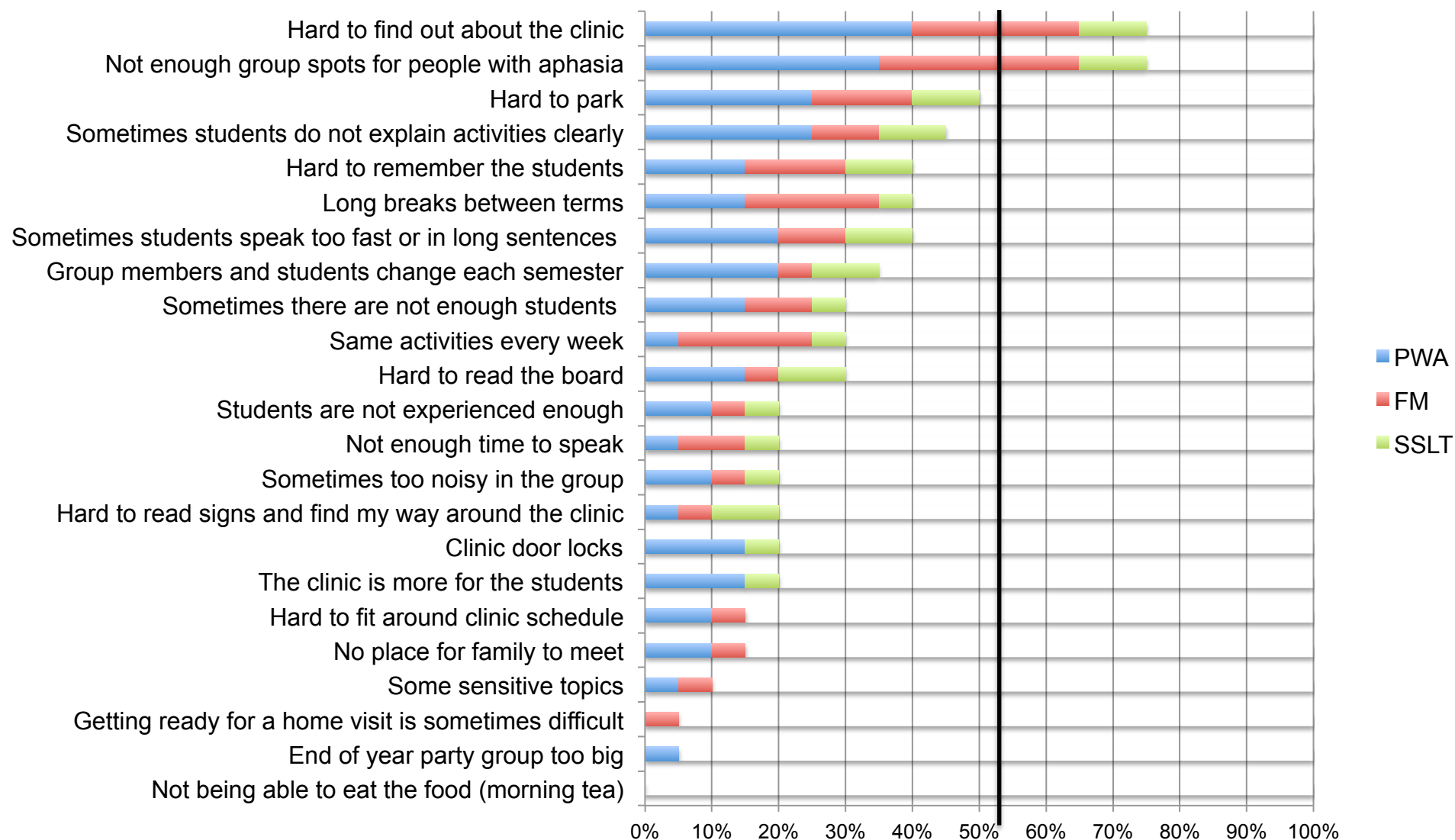
Table 9: Important facilitators for access to the university aphasia clinic, as identified by each participant group.

Facilitator	PWA	FM	SSLT
More advertising about the clinic	✓	✓	✓
Referral from hospital/community	✓	✓	✓
Meeting other people with aphasia and their families (e.g. friendships, support)	✓	✓	✓
People having a similar level of aphasia	✓	✓	✓
[Name of clinic co-ordinator], the clinic co-ordinator, is friendly and understanding	✓	✓	✓
Students are helpful and friendly	✓	✓	
Knowing people at the group	✓	✓	✓
Having their family/friend come with them to the clinic	✓	✓	✓
Small group size	✓	✓	
Breaking into small groups	✓	✓	✓
One on one time with the students	✓	✓	✓
Staying with the same student over the semester	✓	✓	✓
Having dates for the clinic ahead of time	✓	✓	✓
Students are flexible with schedules	✓	✓	✓
2 sessions/week and good length and pace of session		✓	✓
Lots of different stimulating activities	✓	✓	✓
Lots of everyday activities (e.g. using money, conversations)	✓	✓	✓
Activities to do at home	✓	✓	✓
Routine each week	✓	✓	
Therapy goals are what the person with aphasia wants	✓	✓	✓
Pictures and written information helps clients understand the activities	✓	✓	✓
Meeting others at end of year party	✓	✓	

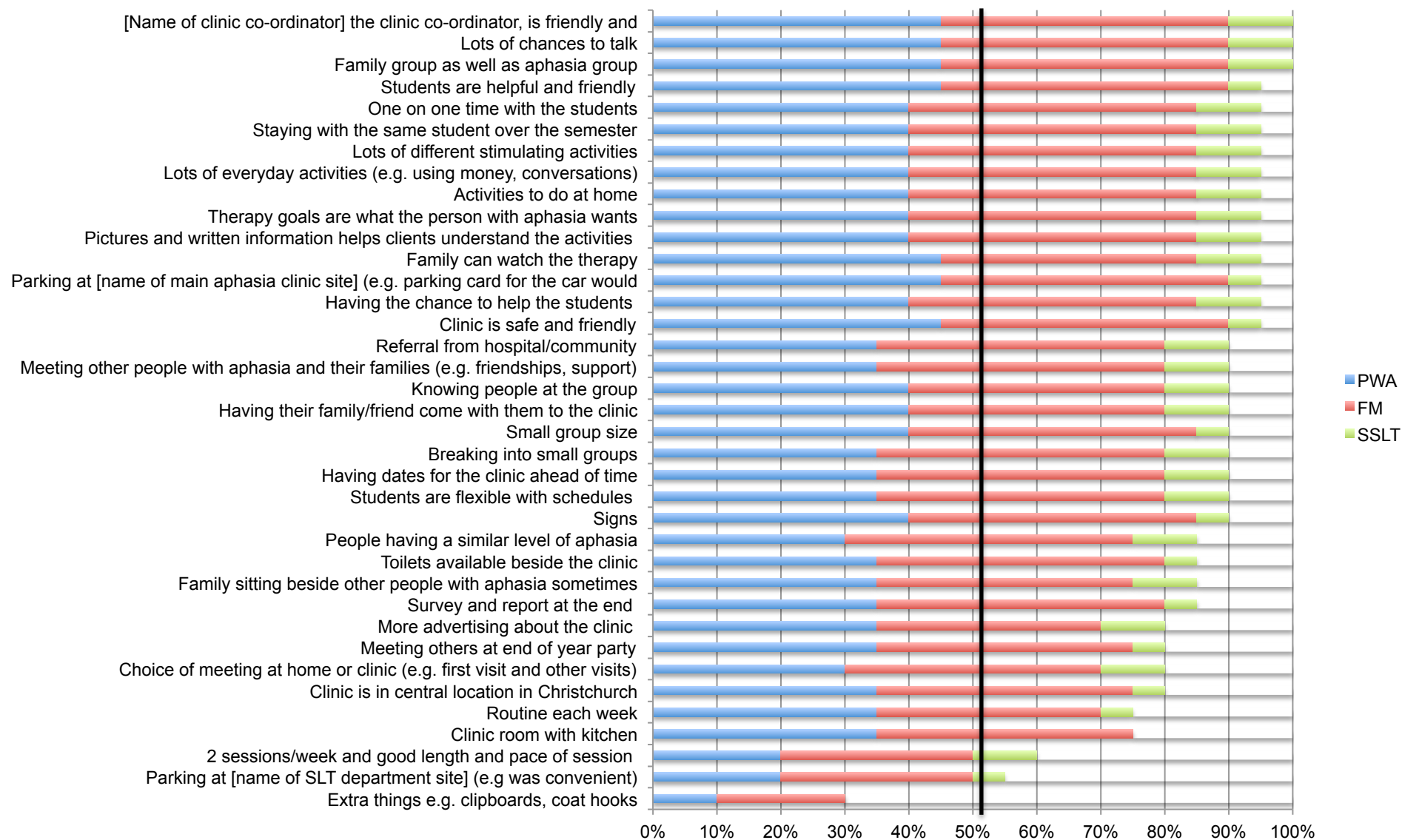
Lots of chances to talk	✓	✓	✓
Family can watch the therapy	✓	✓	✓
Family group as well as aphasia group	✓	✓	✓
Choice of meeting at home or clinic (e.g. first visit and other visits)	✓	✓	✓
Clinic is in central location in Christchurch	✓	✓	
Clinic room with kitchen	✓	✓	
Toilets available beside the clinic	✓	✓	
Parking at [name of speech-language therapy department site] (e.g. was convenient)		✓	
Parking at [name of main aphasia clinic site] (e.g. parking card for the car would help)	✓	✓	
Signs	✓	✓	
Family sitting beside other people with aphasia sometimes	✓	✓	✓
Having the chance to help the students	✓	✓	✓
Clinic is safe and friendly	✓	✓	
Survey and report at the end	✓	✓	

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**Figure A:** Percentages of participants' identification of important barriers to accessing the university aphasia clinic. The solid black, vertical line (51%) represents the threshold of importance



**Figure B:** Percentages of participants' identification of important facilitators for accessing the university aphasia clinic. The solid black, vertical line (51%) represents the threshold of importance



## **Discussion**

This study investigated the barriers and facilitators that influence the access of adults with aphasia. The first round of this modified Delphi study revealed 23 barriers in eight categories and 37 facilitators in nine categories that influence the access of adults with aphasia and their family members/friends to a university outpatient speech-language therapy aphasia clinic from the perspectives of the adult clients with aphasia, their family members/friends who accompany them to the clinic, and the fourth year speech-language therapy (SLT) students involved in the clinic. A questionnaire developed from the analysis of the first round data collected round was administered to all three participant groups in order to obtain a consensus regarding the most important barriers and facilitators. In the second round, the participants identified two of the original 23 barriers and 36 of the original 37 facilitators as being important. These results are discussed below, followed by an outline of the clinical implications, limitations of the study, and recommendations for further research.

### **Most important barriers**

Only two of the 23 barriers were identified as being important by all the participant groups in round two. One barrier involved difficulties finding out about the university clinic, with participants with aphasia and family member participants reporting that they often found out about the service through word of mouth. Many family member participants reported that they received a large quantity of health information related to their spouse's stroke, such as brochures, folders, and written advice from health professionals. They reported that it could be difficult to 'filter' through the resources to find out about the most relevant services to them, such as information about the university aphasia clinic. Receiving large amounts of information is consistent with findings from Aleligay, Worrall, and Rose (2008), where 84 different written health materials (and 114 overall) were acquired from 18 participants with aphasia, demonstrating that families can receive a great amount of health

information following stroke. In addition, one family member participant reported that the university was not the place they would have initially checked for aphasia services, highlighting a lack of knowledge of the service existing at the university within the community. Suggestions from participants included spreading awareness of the clinic among other affiliated organisations, and listing the university clinic on relevant websites.

The second barrier that was identified as being important by a majority of the participants was the limited that the service could only serve a small proportion of the community due to the limited number of places for clients in the programme. Interestingly, in the second round, when asked to what extent they agreed with more advertising about the clinic, some participants commented that they would prefer not to share information about the clinic so as not to lose their place in the programme to other potential clients. Similar organisational barriers have been reported previously in the literature, such as services not being easily accessible due to long waiting lists (Le Dorze, 2010).

### **Most important facilitators**

Some of the most important facilitators involved the relationships with the other people involved in the clinics. The clinic co-ordinator being friendly and understanding was an important facilitator identified by 100% of participants in the second round. Similarly, all participants except for one student speech-language therapy participant agreed that the students were helpful and friendly, which contributed positively to the clinic experience. During the qualitative interviews in the first round, participants with aphasia and family member participants often spoke positive about the relationships they had formed with the clinic co-ordinator and/or students. Words to describe the facilitative attitudes of the clinic co-ordinator and the students included 'kind', 'reassuring', 'accepting', 'dedicated', 'encouraging', and 'patient'. This finding is consistent with the research underlying the *SMARTER* framework (Hersh, Worrall, Howe, Sherratt, & Davidson, 2012), which found that a key aspect of the goal-setting process for aphasia rehabilitation is that it is relationship-centred. Similarly, positive professional attitudes have also been described as a facilitator by Hallé (2014) and the therapeutic value of

developing relationships during aphasia group therapy was highlighted in another study involving student speech-language therapists and clients with aphasia (Cubirka, Barnes, & Ferguson, 2015).

Hersh (2009) found that some of her participants missed the company of their therapist and were therefore saddened by therapy ending. Similarly, participants in this study described missing the students when the semester ended; highlighting the significance of the relationship they had with them. In addition, participants reported that they continued to have contact with their previously assigned student SLTs following the end of the year, such as a visit to their home for a cup of tea.

Eighteen of the 20 participants reported that having the opportunity to meet and build relationships with other people with aphasia and their families was also an important facilitator in the clinic. In the first round, many participants with aphasia and their family member/friend participants reported that they enjoyed the extra opportunity for social contact in the clinic, particularly among those who were understanding and in the same situation as them. Many of these participants reported that they could be 'themselves' and feel accepted as they were in a non-judgemental, welcoming environment. As a result, people with aphasia were less nervous to practice their communication skills in the group, and felt people with aphasia had more opportunities to share their opinion in a therapeutic environment. In addition, meaningful relationships were formed among the clients, with some participants describing other people with aphasia and their families as a 'special' group of people to them. Some participants discussed that meeting other people with aphasia and their family members/friends resulted in them trying and enjoying new activities they would not have thought of otherwise, having been inspired by other group members. These facilitators for access described above are consistent with research on the benefits of aphasia groups (Rotherham, Howe, & Tillard, 2015), demonstrating a successful and motivating therapy model for aphasia rehabilitation.

Many important facilitators identified in the second round involved the therapy activities participants experienced at the clinic, such as having a wide variety of stimulating activities, having the opportunity to practice functional everyday skills, as well as being given advice for tasks to do at home. In

addition, many participants felt the activities were aimed at their abilities, without being overwhelming. This is consistent with research that found people with aphasia enjoyed activities in aphasia or stroke groups that were stimulating, but not too challenging (Rotherham et al., 2015). Having activities supported by visual and written information was additionally identified as a facilitative strategy, supporting the notion of a total communication approach to therapy, including adaptations to written information in an 'aphasia-friendly' format (Rose, Worrall, Hickson, & Hoffmann, 2011).

Having plenty of opportunities for communication at the university clinic was identified as an important facilitator by participants in the study, achieving 100% consensus. This facilitator included opportunities to speak in front of a group, and contributing to group discussion. This finding is consistent with findings from other studies that examined aphasia services at universities (Purves, Petersen, & Puurveen, 2013), as well as research that investigates the benefits of aphasia groups (Rotherham et al., 2015).

Another important facilitator identified by 100% of participants in this study was the desire for increased support for family members in addition to the running of the aphasia group. The need to be involved in rehabilitation with family members suggesting their own therapy goals was also identified in previous research (Howe et al., 2012). During round one, family member participants spoke of one information session for family members of people with aphasia that was offered at the university. They recalled this as a memorable experience and suggested more sessions similar to this should be held in the future. At the time of conducting round two, family member participants reported they had started an informal family support group outside of the university clinic, where family members of people with aphasia could meet for lunch or coffee. Several family members discussed the possibility of having 'more options' organised by the university clinic for family members, such as a regular family group running at the same time as the aphasia group, or regular opportunities to meet family members of the other aphasia group. Furthermore, the literature suggests that the ability of speech-language therapists to support the needs of family members is currently limited, with therapists reporting they often have limited or no goals for family members (Sherratt et al., 2011).



A number of physical aspects of the clinic were also identified as being important facilitators. For example, the colour coding of university buildings was reported to be a facilitator where the main aphasia clinic site was located, as this helped participants with navigation to the correct block of buildings. This is congruent with findings from Howe, Worrall, and Hickson (2008), where colour coded community environments were found to be facilitative.

Another important facilitator involved parking. This finding highlights the importance of physical adaptations to the environment, such as an increased availability of disability car parks at the university aphasia clinic site. The need to have access to adaptations to the physical environment, including environments related to transport is also emphasised in other studies (Le Dorze, 2010), from the views of family members who are typically the ones responsible for arranging transport. Other important physical facilitators included the availability of toilets close to the clinic, and the location of the clinic in a central area of the city.

Another physical facilitator that was found to be important was family members being able to position themselves with someone less familiar in the aphasia group, so that their significant other/friend would not have the opportunity to rely on their help during communication. Similar findings were also reported by Grawburg, Howe, Worrall, and Scarinci (2013), where family members described taking a step back to allow the person with aphasia to attempt communication first, and assisting them only when required.

Participants also identified that having the opportunity to help the students with their clinical experience at the university was an important facilitator. This corresponding theme of altruism and contribution to society was also evident in the literature, where participants with aphasia reported that volunteering to help student speech-language therapists was one of their goals (Purves et al., 2013; Worrall et al., 2011).

While participants reported enjoyment of assisting the students with their studies, a tension between providing a clinical placement for students, and an effective clinical service for clients was noted. For example, some participants felt the university clinic's primary role was to teach the students, with rehabilitating clients as the second priority. In addition, participants speculated that students were more likely to be concerned about their

performance in front of the group, as well as their study workload, therefore compromising the quality of care for the clients. This is congruent with reports by student speech-language therapists that they worried about balancing university demands with their commitment and responsibility to clients (Purves et al., 2013). However, participants in this study also reported feeling that their presence was beneficial for the students' learning as well as their own. Similarly, Purves et al. (2013) also found that both people with aphasia and students acknowledged a reciprocal learning partnership with one another as a facilitator, encouraging the promotion of clients with aphasia as mentors to students. In addition, this teaching role was discussed as a vehicle to develop a positive identity for people with aphasia (Worrall, Davidson, Howe, & Rose, 2007). This was reiterated by one participant with aphasia in this study who felt that the experience of helping students nurtured a positive role in her life.

### **Differences between groups**

One barrier considered important by a majority of participants with aphasia and student speech-language therapy participants in round two, but not by family member/friend participants was when students did not explain activities clearly. It is possible, that because family members would not be part of this communication dyad, they may not be as aware of this barrier as the participants with aphasia and the student speech-language therapy participants. The importance of communication training for student speech-language therapists also has been highlighted in recent studies (Cubirka et al., 2015; Finch et al., 2013). Reasons for not explaining activities clearly may include the students' lack of confidence and limited clinical experience with aphasia (Cubirka et al., 2015), demonstrating a need to support the students' learning of communication skills, which are necessary for interacting with people who have aphasia. In addition, empirical evidence shows that people with aphasia can participate effectively with those who have been trained in supportive conversation techniques (Aura Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001), and therefore have more communicative access to their environment. As such, the results of this study have implications for supporting specialised communication training for student SLTs, not only to

increase knowledge and practical use of strategies, but also to reduce student anxiety on clinical placements, which could lead to communication breakdowns (Cubirka et al., 2015).

### **Clinical implications**

The study highlights a number of clinical implications. First, in addition to improving the accessibility of the specific university clinic that was the focus of this study, the findings can be used to inform the development of more accessible services in other outpatient speech-language therapy clinics. Another key clinical implication is the need for families and individuals with aphasia to access health information that is relevant but not overwhelming (Le Dorze, 2010), as this can affect the ability to filter appropriate information specific to their needs, such as knowing the existence of a university aphasia therapy service. Families and individuals with aphasia may need written information about services that is more tailored to their individual needs and that is supported by verbal input from referring speech therapists. In addition, the type of aphasia service provided could influence how information about that service is shared. For example, serving a small number of clients on a long-term, regular basis may discourage clients from wanting to share information about that service; in fear of losing their place on the programme and therapy coming to an end. This also has implications to support good practice regarding the discharge process, as should be modelled at university and workplace settings (Hersh & Cruice, 2010).

Another clinical implication from the study is that it reinforces the importance of providing relationship-based care, where both clinicians and clients share aspects of themselves with each other; resulting in a valued reciprocal partnership that can enhance therapeutic outcomes (Hersh et al., 2012). Another key finding is the benefit of people with aphasia and their families having the opportunity to meet others in similar situations. This can help clients to identify with one another, have the opportunity to build meaningful friendships, and provide a safe environment for social participation (Rotherham et al., 2015).

This study also adds to the literature by highlighting the need for family support during aphasia rehabilitation (Grawburg et al., 2013). Family members are often the ones to care for the person with aphasia (World Health Organization [WHO], 2011), therefore meeting their needs can enable better outcomes for the person with aphasia.

Supporting increased opportunities for people with aphasia to have conversations has been emphasised as an important facilitator in this study. It is therefore essential that communication partners, such as student speech-language therapists who facilitate the sessions, be trained in facilitatory communication approaches such as the supported conversation approach for adults with aphasia (Kagan et al., 2001), in order to increase communication access for the person with aphasia, and reduce student anxiety on placements (Cubirka et al., 2015).

The unique way of gathering information for this study has benefits for clinical implications. Firstly, data was collected face-to-face in both rounds for the participants with aphasia, which allowed more detailed, rich information to be captured than would normally be found in other Delphi techniques. Secondly, the process of obtaining a consensus from participants reiterates the importance of gaining consumer opinion to inform a service (Hinckley, Boyle, Lombard, & Bartels-Tobin, 2014), which is recommended in the absence of an evidence base that is rigorous (Power et al., 2015). In this case, the findings in this study can be used to inform an index of accessibility of the university aphasia clinic, as well as other similar services. This approach fits with the World Report on Disability's recommendation of consulting and actively involving people with disabilities in formulating and implementing services (World Health Organization, 2011, p.18).

### **Limitations and recommendations for future research**

There are a number of limitations of the study that need to be considered. One limitation was the lack of ethnic diversity among the participants with aphasia and the family member/friend participants, as all were New Zealand European. Therefore, participation access for Maori and Pacifica people with aphasia may need to be specifically addressed in future

investigations, as promoting access and inclusion are objectives of the New Zealand Disability Strategy (Health, 2001). Additionally, the participants with aphasia in this study were mostly male, and the family member participants were mostly female. Moreover, although five student speech-language therapy students initially consented to take part at the start of the investigation, only two students completed both rounds of research. One factor that could have contributed to this lack of student participants was that because of a delay in obtaining ethical approval, the students were not able to be invited to participate in the study until after they had completed their final academic year. As a result, many of the students were possibly no longer accessing their university e-mail accounts. Further research investigating barriers and facilitators for access to speech therapy outpatient services from the perspectives of speech-language therapists is recommended.

Another limitation of the current study may have been that the investigation focused on individuals who were already enrolled in the university aphasia clinic. People with aphasia and their family members who had not accessed the clinic were excluded. As a result, barriers that these individuals may have experienced in attempting to access the clinic were not identified. Future research could focus on investigating barriers to accessing outpatient speech therapy services from the perspectives of people with aphasia and their families who are not currently enrolled in the service or who had left the service.

Although there were several benefits of using face-to-face encounters with people with aphasia during round two of the current study, the process of completing the questionnaire was extremely lengthy for one participant with aphasia. Although the researcher indicated that she could complete the interview over shorter sessions, the participant chose to continue with the interview in an effort to complete the research task. This issue would need to be considered in future studies involving the Delphi technique with people with aphasia.

Finally, more research is required to investigate the access to other outpatient speech language therapy services, to add to and inform a universal framework for outpatient speech-language therapy service accessibility. This could benefit not only those with aphasia and their families, but become

advantageous for a wider range of people with communication difficulties and their families (Kagan & LeBlanc, 2002; Worrall, Rose, Howe, McKenna, & Hickson, 2007).

## **Conclusion**

This study has identified a range of important barriers and facilitators that were perceived to influence access to an outpatient speech-language therapy aphasia clinic. The findings from this study may be helpful for addressing existing barriers to speech-language services, as well as other health services, for people with aphasia and their families, while suggesting potential facilitators to reduce the barriers that affect accessibility.

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## **APPENDIX A - Human ethics committee approval**



### **HUMAN ETHICS COMMITTEE**

Secretary, Lynda Griffioen  
Email: [human-ethics@canterbury.ac.nz](mailto:human-ethics@canterbury.ac.nz)

Ref: HEC 2014/145

19 November 2014

Cassandra Chow  
Department of Communication Disorders  
UNIVERSITY OF CANTERBURY

Dear Cassandra

The Human Ethics Committee advises that your research proposal “Barriers and facilitators that affect access to the University of Canterbury speech-language therapy asphasia clinic” has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 17 November 2014.

Best wishes for your project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'L. MacDonald'.

Lindsey MacDonald  
**Chair**  
***University of Canterbury Human Ethics Committee***

**Printed on UC letterhead**

**APPENDIX B - Demographic information form – Participant with aphasia**

**Participant ID#\*:**

**Name:**

**Address:**

**Phone:**

**Email:**

**\*This page with contact details was stored separately from the remaining pages of the demographics information form and research data.**

## APPENDIX B

Participant I.D:

Date Completed:

1. Your current age:

2. Your gender:

3. Where do you live?

- ☐ In my own home with \_\_\_\_\_ adults and \_\_\_\_\_ children
- ☐ Alone in my own home
- ☐ In a care facility
- ☐ Other, please state: \_\_\_\_\_

4. What is your highest level of education?

- ☐ Completed some primary school
- ☐ Completed primary school
- ☐ Completed some high school
- ☐ Completed high school
- ☐ Completed an undergraduate certificate or diploma
- ☐ Completed an undergraduate degree
- ☐ Completed a post-graduate degree, diploma or certificate
- ☐ Other, please state: \_\_\_\_\_

5. What is your first language? \_\_\_\_\_

6. What other languages do you speak? \_\_\_\_\_

7. What ethnic groups do you belong to?

☐ New Zealand European

☐ Māori

☐ Samoan

☐ Cook Island Maori

☐ Tongan

☐ Niuean

☐ Chinese

☐ Indian

☐ Other, please state \_\_\_\_\_

8. How many strokes have you had? \_\_\_\_\_

9. What was the date of your stroke/s: \_\_\_\_\_

10. Were you working just before you had your stroke? \_\_\_\_\_

If yes, what was your job before your stroke?

\_\_\_\_\_

11. Are you working now? \_\_\_\_\_

If yes, what is your current role?

\_\_\_\_\_

12. How do you usually travel to the clinic?

☐ Family member/friend drives me in a car

☐ I drive

☐ Bus

☐ Taxi

☐ Walk

☐ Other, please state: \_\_\_\_\_

**13. Do you use reading glasses at the clinic?**

☐ Yes, always

☐ Yes, sometimes

☐ No, I have them but do not wear

☐ No, I don't have reading glasses

**14. Do you wear hearing aids at the clinic?**

☐ Yes, always

☐ Yes, sometimes

☐ No, I have them but do not wear

☐ No, I don't have hearing aids

**15. Do you use a walking stick or walking frame when coming to the clinic?**

☐ Yes, always

☐ Yes, sometimes

☐ No

**16. Do you use a wheelchair when coming to the clinic?**

☐ Yes, always

☐ Yes, sometimes

☐ No

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**APPENDIX C - Demographic information form - Family  
Member/Accompanying Person Participant**

**Participant ID#\*:**

**Name:**

**Address:**

**Phone:**

**Email:**

**\*This page with contact details was stored separately from the remaining pages of the demographics information form and research data.**

Participant I.D:

Date Completed:

## APPENDIX C

1. Your current age:
2. Your gender:
3. What is your highest level of education?
  - ☐ Completed some primary school
  - ☐ Completed primary school
  - ☐ Completed some high school
  - ☐ Completed high school
  - ☐ Completed an undergraduate certificate or diploma
  - ☐ Completed an undergraduate degree
  - ☐ Completed a post-graduate degree, diploma or certificate
  - ☐ Other, please state: \_\_\_\_\_
4. What is your first language? \_\_\_\_\_
5. What other languages do you speak? \_\_\_\_\_
6. What ethnic groups do you belong to?
  - ☐ New Zealand European
  - ☐ Māori
  - ☐ Samoan
  - ☐ Cook Island Maori
  - ☐ Tongan
  - ☐ Niuean
  - ☐ Chinese
  - ☐ Indian
  - ☐ Other, please state: \_\_\_\_\_
7. What is your relationship to the person with aphasia who comes to the clinic?
  - ☐ Family member (please state your relationship to the person – e.g. son of): \_\_\_\_\_
  - ☐ Friend
  - ☐ Paid carer
  - ☐ Other, please state: \_\_\_\_\_
8. How long have you known the person with aphasia?  
\_\_\_\_\_ years or \_\_\_\_ months
9. How often have you accompanied the person with aphasia to the clinic?

- ☐ Never
- ☐ 1 time
- ☐ 2-5 times
- ☐ 6-10 times
- ☐ 10 times to almost every time the person with aphasia has attended the clinic
- ☐ Every time the person with aphasia has attended the clinic

10. How do you usually travel to the clinic?

- ☐ Family member/friend drives me in a car
- ☐ I drive
- ☐ Bus
- ☐ Taxi
- ☐ Walk
- ☐ Other, please state: \_\_\_\_\_

11. Do you use reading glasses at the clinic?

- ☐ Yes, always
- ☐ Yes, sometimes
- ☐ No, I have them but do not wear
- ☐ No, I don't have reading glasses

12. Do you wear hearing aids at the clinic?

- ☐ Yes, always
- ☐ Yes, sometimes
- ☐ No, I have them but do not wear
- ☐ No, I don't have hearing aids

13. Do you use a walking stick or walking frame when coming to the clinic?

- ☐ Yes, always
- ☐ Yes, sometimes
- ☐ No

14. Do you use a wheelchair when coming to the clinic?

- ☐ Yes, always
- ☐ Yes, sometimes
- ☐ No



**Printed on UC letterhead**

**APPENDIX D - Demographic information form – Speech-Language  
Therapy Student Participant**

**Participant ID#\*:**

**Name:**

**Address I can be contacted at until the end of 2014/early 2015:**

**Phone:**

**Email I can be contacted at until the end of 2014/early 2015:**

**\*This page with contact details was stored separately from the remaining pages of the demographics information form and research data.**

**Participant I.D:**

**Date Completed:**

## **APPENDIX D**

**1. Your current age:**

- ☐ 18-29 years
- ☐ 30-39 years
- ☐ 40-49 years
- ☐ 50-65 years

**2. Your gender:**

**3. What ethnic groups do you belong to?**

- ☐ New Zealand European
- ☐ Māori
- ☐ Samoan
- ☐ Cook Island Maori
- ☐ Tongan
- ☐ Niuean
- ☐ Chinese
- ☐ Indian
- ☐ Other, please state: \_\_\_\_\_

**4. How many different clients with aphasia have you seen in the individual therapy sessions at the University of Canterbury aphasia clinic in 2014?**

\_\_\_\_\_

**5. How many different clients with aphasia have you seen in the group sessions at the University of Canterbury aphasia clinic in 2014?**

\_\_\_\_\_

**6. How many weeks did you participate in the clinic in 2014? \_\_\_\_\_**

**7. What other experiences have you had working as a speech-language therapy student with people with aphasia?**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## **APPENDIX E – Round 1 - Interview topic guide for participants with aphasia**

### **Interview Topic Guide**

#### **Barriers/What made it hard:**

1. What makes it hard for you and (insert name of person who accompanies them to the clinic) **to access and take part in the clinic?**
2. What made it hard for you and (insert name of person who accompanies them to the clinic) **to find out about the clinic?**
3. What made it hard for you and (insert name of person who accompanies them to the clinic) **to take part in the first visit to your home?**
4. What made it hard for you and (insert name of person who accompanies them to the clinic) **to take part in the group sessions?**
5. What made it hard for you and (insert name of person who accompanies them to the clinic) **to take part in the individual therapy sessions?**
6. What made it hard for you and (insert name of person who accompanies them to the clinic) **to start a new therapy block?**
7. What made it hard for you and (insert name of person who accompanies them to the clinic) **to end a therapy block?**
8. Did anything else make it hard for you and (insert name of person who accompanies them to the clinic) **to access and take part in the clinic? If yes, what?**

#### **Facilitators/What helps/could help you:**

9. What helps you and (insert name of person who accompanies them to the clinic) **to access and take part in the clinic?**
10. What helped you and (insert name of person who accompanies them to the clinic) **to find out about the clinic?**
11. What helped you and (insert name of person who accompanies them to the clinic) **to take part in the first visit to your home?**
12. What helped you and (insert name of person who accompanies them to the clinic) **to take part in the group sessions?**
13. What helped you and (insert name of person who accompanies them to the clinic) **to take part in the individual therapy sessions?**
14. What helped you and (insert name of person who accompanies them to the clinic) **to start a new therapy block?**
15. What helped you and (insert name of person who accompanies them to the clinic) **to end a therapy block?**
16. Did anything else help you and (insert name of person who accompanies them to the clinic) **to access and take part in the clinic? If yes, what?**

**APPENDIX F – Round 1 - Questionnaire for family  
member/accompanying person participants**

**(Note: there were two questions per page in the final questionnaire if provided in paper form).**

**Participant ID #:**

**Date completed:**

Thank you for taking the time to complete this questionnaire. We want to know what makes it hard (i.e. barriers) and what helps (i.e. facilitators) people with aphasia and their family members/individuals who accompany them when accessing the University of Canterbury aphasia clinic. For this study, we consider access to mean being able to enter and to take part in the service. The information you provide will help us to improve the clinic in the future.

Please answer the following 16 questions in the space provided. If you require more space, please attach extra pages and indicate the question number you are responding to. The questionnaire should take approximately 20-30 minutes to complete. If you have any questions, please feel free to e-mail me at [cassandra.chow@pg.canterbury.ac.nz](mailto:cassandra.chow@pg.canterbury.ac.nz) or to phone me on 021889426.

**What makes it hard (i.e. barriers):**

- 1. What, if anything, has made it hard for you and the person with aphasia to access and take part in the university aphasia clinic?**
- 2. What, if anything, made it hard for you and the person with aphasia to find out about the university aphasia clinic?**
- 3. What, if anything, made it hard for you and the person with aphasia to take part in the first visit to the home of the person with aphasia?**
- 4. What, if anything, made it hard for you and the person with aphasia to take part in the group sessions?**

5. What, if anything, made it hard for you and the person with aphasia **to take part in the individual therapy sessions?**
6. What, if anything, made it hard for you and the person with aphasia **to start a new therapy block?**
7. What, if anything, made it hard for you and the person with aphasia **to end a therapy block?**
8. Did **anything else** make it hard for you and the person with aphasia to access and take part in the university aphasia clinic? If yes, what?

**What helps/could help (i.e. facilitators):**

9. What, if anything, has helped/could help you and the person with aphasia **to access and take part in the university aphasia clinic?**
10. What, if anything, has helped/could help you and the person with aphasia **to find out about the university aphasia clinic?**
11. What, if anything, has helped/could help you and the person with aphasia **to take part in the first visit to the home of the person with aphasia?**
12. What, if anything, has helped/could help you and the person with aphasia **to take part in the group sessions?**
13. What, if anything, has helped/could help you and the person with aphasia **to take part in the individual therapy sessions?**
14. What, if anything, has helped/could help you and the person with aphasia **to start a new therapy block?**
15. What, if anything, has helped/could you and the person with aphasia **to end a therapy block?**
16. Did **anything else** help you, or could anything else help you and the person with aphasia to access and take part in the university aphasia clinic? If yes, what?

**APPENDIX G – Round 1 - Questionnaire for speech-language therapy student participants**

**(Note: there were two questions per page in the final questionnaire if provided in paper form).**

**Participant ID #:**

**Date completed:**

Thank you for taking the time to complete this questionnaire. We want to know what makes it hard (i.e. barriers) and what helps (i.e. facilitators) people with aphasia and their family members/individuals who accompany them when accessing the University of Canterbury aphasia clinic. For this study, we consider access to mean being able to enter and to take part in the service. The information you provide will help us to improve the clinic in the future.

Please answer the following 16 questions in the space provided. If you require more space, please attach extra pages and indicate the question number you are responding to. The questionnaire should take approximately 20-30 minutes to complete. If you have any questions, please feel free to e-mail me at [cassandra.chow@pg.canterbury.ac.nz](mailto:cassandra.chow@pg.canterbury.ac.nz) or to phone me on 021889426.

**What makes it hard (i.e. barriers):**

1. What, if anything, do you perceive has made it hard for the clients with aphasia and the family members/individuals who accompany them **to access and take part in the university aphasia clinic?**
2. What, if anything, do you perceive has made it hard for the clients with aphasia and the family members/individuals who accompany them **to find out about the university aphasia clinic?**
3. What, if anything, do you perceive has made it hard for the clients with aphasia and the family members/individuals who

accompany them **to take part in the first visit to the home of the individual with aphasia?**

4. What, if anything, do you perceive has made it hard for the clients with aphasia and the family members/individuals who accompany them **to take part in the group sessions?**
5. What, if anything, do you perceive has made it hard for the clients with aphasia and the family members/individuals who accompany them **to take part in the individual therapy sessions?**
6. What, if anything, do you perceive has made it hard for the clients with aphasia and the family members/individuals who accompany them **to start a new therapy block?**
7. What, if anything, do you perceive has made it hard for the clients with aphasia and the family members/individuals who accompany them **to end a therapy block?**
8. Do you perceive **anything else** makes it hard for the individuals with aphasia and the family members/individuals who accompany them to access and take part in the university aphasia clinic?

**What helps/could help (i.e. facilitators):**

9. What, if anything, do you perceive has helped/could help the clients with aphasia and the family members/individuals who accompany them **to access and take part in the university aphasia clinic?**
10. What, if anything, do you perceive has helped/could help the clients with aphasia and the family members/individuals who accompany them **to find out about the university aphasia clinic?**
11. What, if anything, do you perceive has helped/could help the clients with aphasia and the family members/individuals who accompany them **to take part in the first visit to the home of the individual with aphasia?**

12. What, if anything, do you perceive has helped/could help the clients with aphasia and the family members/individuals who accompany them **to take part in the group sessions?**
13. What, if anything, do you perceive has helped/could help the clients with aphasia and the family members/individuals who accompany them **to take part in the individual therapy sessions?**
14. What, if anything, do you perceive has helped/could help the clients with aphasia and the family members/individuals who accompany them **to start a new therapy block?**
15. What, if anything, do you perceive has helped/could help the clients with aphasia and the family members/individuals who accompany them **to end a therapy block?**
16. Do you perceive **anything else** that has helped or could help the individuals with aphasia and the family members/individuals who accompany them to access and take part in the university aphasia clinic?



APPENDIX H (printed on UC letterhead)

**Obtaining information from the University of  
Canterbury Speech-Language Therapy Clinic Form**

I, \_\_\_\_\_ agree to allow



Gina Tillard, University of Canterbury Aphasia Clinic  
Director to give the following information:

- my **Western Aphasia Battery – Revised Test** subtest and total scores, and the date it was given
- the date I started the clinic
- the number of times I have attended the clinic

to the University of Canterbury **researcher**  
**Cassandra Chow**

for the research called “**Barriers and facilitators that  
affect access to the University of Canterbury speech-  
language therapy aphasia clinic.**”

I understand that this information will remain **confidential**.

**CONFIDENTIAL**

\_\_\_\_\_  
Signature of participant

\_\_\_\_\_  
Date

**APPENDIX I – Example question from round 2 questionnaire for participants with aphasia**

---



**An important thing that helps people with aphasia and their families to take part in the clinic is:**

**Signs**



				
strongly disagree	disagree	Neither agree nor disagree	agree	strongly agree

## **APPENDIX J – Round 2 questionnaire for family members/friends/student speech-language therapists**

**(Note: Participant numbers and dates were included on each document.)**

Listed below are the facilitators and barriers to accessing the speech and language therapy aphasia service at the University of Canterbury, reported by all the participants of this study.

Please indicate to what extent you agree or disagree with each statement.

<b>Facilitators</b>					
An <b>important thing</b> that <b>helps/could help</b> people with aphasia and their families to take part in the clinic is:					
	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neither agree nor disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
More advertising about the clinic					
Referral from hospital/community					
Meeting other people with aphasia and their families (e.g. friendships, support)					
People having a similar level of aphasia					
Chris, the clinic co-ordinator, is friendly and understanding					
Students are helpful and friendly					
Knowing people at the group					
Having their family/friend come with them to the clinic					
Small group size					
Breaking into small groups					
One on one time with the students					
Staying with the same student over the semester					
Having dates for the clinic ahead of time					
Students are flexible with schedules					
2 sessions/week and good length and pace of session					
Lots of different stimulating activities					

An **important thing** that **helps/could help** people with aphasia and their families to take part in the clinic is:

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
Lots of everyday activities (e.g. using money, conversations)					
Activities to do at home					
Routine each week					
Therapy goals are what the person with aphasia wants					
Pictures and written information helps clients understand the activities					
Meeting others at end of year party					
Lots of chances to talk					
Family can watch the therapy					
Family group as well as aphasia group					
Choice of meeting at home or clinic (e.g. first visit and other visits)					
Clinic is in central location in Christchurch					
Clinic room with kitchen					
Toilets available beside the clinic					
Parking at Creyke Road (e.g. was convenient)					
Parking at Kirkwood (e.g. parking card for the car would help)					
Signs					
Family sitting beside other people with aphasia sometimes					
Having the chance to help the students					
Clinic is safe and friendly					
Survey and report at the end					
Extra things e.g. clipboards, coat hooks					

## Barriers

An **important thing** that **makes it hard** for the people with aphasia and their families to take part in the clinic is:

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
Hard to find out about the clinic					
Hard to remember the students					
Students are not experienced enough					
Sometimes there are not enough students					
Group members and students change each semester					
Not enough group spots for people with aphasia					
Hard to fit around clinic schedule					
Long breaks between terms					
Getting ready for a home visit is sometimes difficult					
Same activities every week					
Some sensitive topics					
End of year party group too big					
Not enough time to speak					
Sometimes too noisy in the group					
Hard to read the board					
Sometimes students speak too fast or in long sentences					
Sometimes students do not explain activities clearly					
No place for family to meet					
Hard to park					
Hard to read signs and find my way around the clinic					
Clinic door locks					
The clinic is more for the students					
Not being able to eat the food (morning tea)					

**APPENDIX K – Recruitment notice for participants with aphasia and family member/friend participants**  
**Research study: Barriers and facilitators that affect access to the University of Canterbury speech-language therapy aphasia clinic**

**We need your help for research!**

**Who do we need?**

- **Adults with aphasia:**
  - who came to the **university aphasia clinic** in 2014.
- **and family members/others:**
  - who came with **adults with aphasia** to the clinic at least once in 2014.

**What is the research about?**

- To find out **what helps you and your family** to access and **take part** in the **university aphasia clinic**.
- **Your opinion** is important to us.

**What will happen?**

- Cassandra Chow will **interview** the people with aphasia two (2) times.
- Family members/others will fill in two written questionnaires.

**To find out more:**

- **contact Cassandra Chow, Department of Communication Disorders MSc student** by [insert date]

**Phone: 021889426**

**Email: [cassandra.chow@pg.canterbury.ac.nz](mailto:cassandra.chow@pg.canterbury.ac.nz)**

- or Dr. Tami Howe

**Email:** [tami.howe@canterbury.ac.nz](mailto:tami.howe@canterbury.ac.nz)

This study has been reviewed and approved by the University of Canterbury Human Ethics Committee.

## **APPENDIX L – Recruitment Notice for student speech-language therapists**

### **Research study: Barriers and facilitators that affect access to the University of Canterbury speech-language therapy aphasia clinic**

## **We need your help for research!**

### **Who do we need?**

- 4<sup>th</sup> year BSLP students who have completed a clinical rotation in the University of Canterbury Speech-language Therapy Aphasia Clinic in 2014.

### **What is the research about?**

- It is important to ensure our aphasia clinics are accessible.
- We want to find out what you perceive makes it hard (i.e. barriers) and what helps (i.e. facilitators) people with aphasia and their family/accompanying individuals to access (to enter and take part) in the university aphasia clinic.
- Your opinion is important to us.

### **What will happen?**

- Fill in two questionnaires either online or in a written format. You can complete the questionnaires at a time and place that is convenient for you.

To find out more about the study, please contact Cassandra Chow on:

Phone: 021889426

Email: [cassandra.chow@pg.canterbury.ac.nz](mailto:cassandra.chow@pg.canterbury.ac.nz)

by [insert date].

or Dr. Tami Howe

Email: [tami.howe@canterbury.ac.nz](mailto:tami.howe@canterbury.ac.nz)

This study has been reviewed and approved by the University of Canterbury Human Ethics Committee.



## APPENDIX M

This was printed on university letterhead.

### **Research Information Sheet – Participants with aphasia**

**Title of project: Barriers and facilitators that affect access to the University of Canterbury speech-language therapy aphasia clinic**

**Researcher: Cassandra Chow**



Email: [cassandra.chow@pg.canterbury.ac.nz](mailto:cassandra.chow@pg.canterbury.ac.nz)



Phone: +64 2188 9426



**Supervisor: Tami Howe**



Email: [tami.howe@canterbury.ac.nz](mailto:tami.howe@canterbury.ac.nz)



Phone: +64 3642987 ext.3619



**Supervisor: Christine Wyles**



Email: [christine.wyles@canterbury.ac.nz](mailto:christine.wyles@canterbury.ac.nz)



Phone: +64 3642987 ext.7106





**Supervisor: Dr. Tanya Rose, University of Queensland**



Email: [t.rose@uq.edu.au](mailto:t.rose@uq.edu.au)

## Research purpose:

To find out:

- **What helps**   
you and your family **to take part**  
**in the university aphasia therapy**  
**clinic?**
- **What makes**   
**it hard** for you and your family **to**  
**take part in the university**  
**aphasia therapy clinic?**

**university  
aphasia clinic**



## Who do we need?

- **People with aphasia** who have been to the **university aphasia clinic** in **2014**.

## What will happen?

- There will be **two (2) interviews**.
- You can have a support person with you during the research.

### Interview One (1):

- Cassie Chow will **interview** you.
- Cassie is a **speech-language therapist**
- Cassie **may use pictures** to make the interview easier.

**Cassie  
Chow**



- The interview will be **video-recorded**.
- Cassie will ask you information such as your age.



## How long?



- About **1 hour**.

## Where will the interview be?

- Cassie will **meet you at your home or other quiet place**



The results from interview one (1) will help us make a **questionnaire** for interview two (2).

## questionnaire



Cassie will ask you to sign a form to find out some information from the university aphasia clinic.

## Interview Two (2):

- Cassie will **interview** you.
- Cassie **may use pictures** to make the interview easier.

## Cassie Chow



## How long?



- About **30 minutes to 1 hour**.

## Where will the interview be?

- Cassie will **meet you at your home or other quiet place.**



## Potential benefits:

- This will **help research.**
- **This is NOT Speech therapy.**
- You do not have to take part – it is **your choice.**  
This will **NOT affect your service** from the university

## Potential risks:

- There is **NO danger in doing** in this research.
- **All information** will be kept **confidential.**
- **Only Cassie Chow**, Dr. Howe, Dr. Rose and research assistants **can access your information.**
- **Chris Wyles** will **NOT** have access to specific information about you.
- **Your information** will be **destroyed after five (5) years.**
- **You can stop at any time.**  
It is **your choice.**
- **If you stop**, you can **ask for your information** to be **destroyed.**



- This will **NOT affect your service** from the **university**.
- The **results** will be **published** as a Master's **thesis**. This is a public document.  
It can be **found** in the **University library**.



☒ The **study** has been reviewed and **approved** by the **University of Canterbury Human Ethics Committee**.



If you have a problem or complaint about this research, contact the Ethics Officer by email: [human-ethics@canterbury.ac.nz](mailto:human-ethics@canterbury.ac.nz)

For more information, contact:

**Cassandra Chow (Cassie)**



Email: [cassandra.chow@pg.canterbury.ac.nz](mailto:cassandra.chow@pg.canterbury.ac.nz)



Phone: +64 2188 9426



## Consent form for participant with aphasia

**Title of Project:** Barriers and facilitators that affect access to the University of Canterbury speech-language therapy aphasia clinic

I understand:



- The **information about this research project** has been **explained** to me.
- I have **had a chance to ask questions**.
- I **understand what I need to do**.

- I **agree** to have the **interview videotaped**.



- I know I **can stop** doing the **study at any time**.



- **Stopping will not affect my service** from the university.

- If I stop, I **can ask for information I have given to be destroyed**.



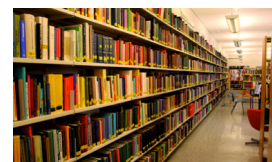
- **Everything will be confidential**.



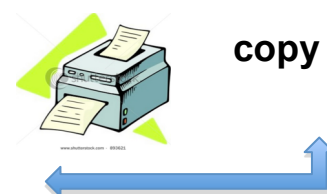
- **My information will be stored securely**.
- **Only the researcher, Dr. Howe, Dr. Rose and research assistants can access the information**.

- I understand **Chris Wyles** will **NOT** be able to **see specific information about me**
- I understand that the **findings may be published** as a thesis.
- A thesis is a **public document**.

- This document can be found in the **University library**.



- I will be **given a copy of this form**.



☐ I want a **copy of the written information about my interview**.

☐ I want a **summary of the research result at the end of the study**.

**By signing my name below, I agree to participate in this research project:**

---

**Signature of Participant**

---

**Name of Participant**

**Date:**

**Email/Home Address:**

**For more information:**

**Researcher: Cassandra Chow**



**Email:** [cassandra.chow@pg.canterbury.ac.nz](mailto:cassandra.chow@pg.canterbury.ac.nz)



**Phone: 02188 9426**





## **APPENDIX N**

**(on UC letterhead)**

### **Research information sheet and consent form – family member/friend participant**

**Title of project: Barriers and facilitators that affect access to the University of Canterbury speech-language therapy aphasia clinic**

Researcher: Cassandra Chow

Email: [cassandra.chow@pg.canterbury.ac.nz](mailto:cassandra.chow@pg.canterbury.ac.nz)

Phone: +64 2188 9426

Research Supervisor: Tami Howe

Email: [tami.howe@canterbury.ac.nz](mailto:tami.howe@canterbury.ac.nz)

Phone: +64 3642987 ext.3619

Research Supervisor: Christine Wyles

Email: [christine.wyles@canterbury.ac.nz](mailto:christine.wyles@canterbury.ac.nz)

Phone: +64 3642987 ext.7106

Research Supervisor: Dr. Tanya Rose, University of Queensland

Email: [t.rose@uq.edu.au](mailto:t.rose@uq.edu.au)

### **What is the purpose of the study?**

We want to learn:

- What helps you and your family member/friend to take part in the university aphasia therapy clinic?
- What makes it hard for you and your family/friend to take part in the university aphasia therapy clinic?

This information will help us to improve the university aphasia therapy clinic.

### **Who are the participants required for the study?**

- A family member, friend or other individual who has accompanied the person with aphasia to the University of Canterbury speech-language therapy aphasia clinic at least once in 2014.

### **What will happen in the study?**

The study has two rounds.

The first round involves completing a questionnaire about what makes it hard for (i.e. barriers) and what helps (i.e. facilitators) people with aphasia and their families to access and take part in the University of Canterbury speech-language therapy aphasia clinic.

The information collected during the first round will be used to develop a second questionnaire about the most important barriers and facilitators that affect access to the aphasia clinic.

You can fill in the questionnaires via e-mail or in a paper format depending on your preference.

You will also be asked to complete a brief information form about your age etc.

You can return all these forms via email or post.

### **How long will the study take?**

- The first questionnaire will take about 20 to 30 minutes to complete.
- The second questionnaire will take about 15 to 20 minutes to complete.
- You can complete the questionnaire at a time that is convenient for you.

### **Where will the study take place?**

You will fill out the questionnaires at a location of your choice.

### **What are the benefits of participating in the study?**

Your participation in this study will help researchers understand how to improve the accessibility of the University of Canterbury speech-language therapy aphasia clinic. However, there may be no direct benefit to you.

### **What are the risks in participating in the study?**

There are no significant risks if you choose to participate in this research.

### **How will confidentiality be maintained?**

- The results of the project will be discussed in a thesis. A thesis is a public document and will be available through the University of Canterbury library.
- The results of the project may be published. Any identifying information about you is kept strictly confidential. Your identity will not be made public without your prior consent.
- Strict confidentiality will be maintained at all times.
- All information about you will be kept in a locked cabinet in the Communication Disorders Department, The University of Canterbury.
- All electronic information about you will be stored in a password-protected database on a computer in a locked office in the Communication Disorders Department, The University of Canterbury.
- Only the research investigator, Dr. Howe, Dr. Rose and research assistants will be able to access the information. Although Chris Wyles is also a research supervisor, she will not have access to specific information about you in this study.
- After the investigation, raw data will be stored in a locked cabinet in a locked office in the Department of Communication Disorders at the University of Canterbury for five years and then destroyed.

### **Can you withdraw from the study?**

You can withdraw from the research study at any time, without reason. You are under no obligation to the researcher. Choosing not to take part in or withdrawing from the study will not affect your relationship with The University of Canterbury. If you withdraw, you can request that the investigator destroy all information already collected from you.

This project is being carried out as a requirement for MSc in Speech and Language Sciences by Cassandra Chow under the supervision of Dr. Tami Howe, who can be contacted at: [\[tami.howe@canterbury.ac.nz\]](mailto:tami.howe@canterbury.ac.nz) and Christine Wyles, who can be contacted at: [\[christine.wyles@canterbury.ac.nz\]](mailto:christine.wyles@canterbury.ac.nz). They will be pleased to discuss any concerns you may have about participation in the project.

This study has been reviewed and approved by The University of Canterbury Human Ethics Committee. If you have any complaints, please contact: The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch ([human-ethics@canterbury.ac.nz](mailto:human-ethics@canterbury.ac.nz)).

Thank you for your interest in this research study.

Cassandra Chow, Grad.Dip.SLT, B.A.(Hons)  
MSc Student, Ph. +6421889426  
Communication Disorders Department  
Telephone: +6421889426  
Email: [cassandra.chow@pg.canterbury.ac.nz](mailto:cassandra.chow@pg.canterbury.ac.nz)

**Note:(on UC letterhead)**  
**Consent form for family member/friend participant**

**Barriers and facilitators that affect access to the University of Canterbury  
speech-language therapy aphasia clinic**

I have been given a full explanation of this project and have had the opportunity to ask questions.

I understand what is required of me if I agree to take part in the research.

I understand that participation is voluntary and I may withdraw at any time without affecting any services I receive from the university. If I withdraw, I can ask for my information to be destroyed.

I understand that any information or opinions I provide will be kept confidential to the researcher, her supervisors and research assistants. Any published or reported results will not identify the participants.

I understand that all data collected for the study will be kept in locked, secure facilities and password protected electronic form and will be destroyed after five years.

Only the researcher, Dr. Howe, Dr. Rose and research assistants can access the information. I understand that although Chris Wyles is also supervising, she will not be able to see specific information that may identify me.

I understand that a thesis is a public document and will be available through the University of Canterbury library.

I have/will be given a copy of this form.

I understand that I can contact the researcher Cassandra Chow [[cassandra.chow@pg.canterbury.ac.nz](mailto:cassandra.chow@pg.canterbury.ac.nz)] or supervisors Tami Howe [[tami.howe@canterbury.ac.nz](mailto:tami.howe@canterbury.ac.nz)] and Christine Wyles [[christine.wyles@canterbury.ac.nz](mailto:christine.wyles@canterbury.ac.nz)] for further information. If I have any complaints, I can contact the Chair of the University of Canterbury Human Ethics Committee, Private Bag 4800, Christchurch ([human-ethics@canterbury.ac.nz](mailto:human-ethics@canterbury.ac.nz))

- ☐ I would like a summary about the research findings sent to me at the end of the study.

By signing below, I agree to participate in this research project

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Participant Name: \_\_\_\_\_

Email Address: \_\_\_\_\_

This form may be returned by via email/post to Cassandra Chow.

**APPENDIX O (on UC letterhead)**  
**Research information sheet – Student speech-language therapists**

**Title of project: Barriers and facilitators that affect access to the  
University of Canterbury speech-language therapy aphasia clinic**

Researcher: Cassandra Chow

Email: cassandra.chow@pg.canterbury.ac.nz

Phone: +64 2188 9426

Research Supervisor: Tami Howe

Email: tami.howe@canterbury.ac.nz

Phone: +64 3642987 ext.3619

Research Supervisor: Christine Wyles

Email: christine.wyles@canterbury.ac.nz

Phone: +64 3642987 ext.7106

Research Supervisor: Dr. Tanya Rose, University of Queensland

Email: t.rose@uq.edu.au

**What is the purpose of the study?**

We want to learn:

- What do you perceive helps your clients and their family members to take part in the university aphasia therapy clinic?
- What do you perceive makes it hard for your clients and their family members to take part in the university aphasia therapy clinic?

This information will help us to improve the university aphasia therapy clinic.

### **Who are the participants required for the study?**

- 4<sup>th</sup> Year University of Canterbury Bachelor's of Speech-Language Pathology students who have completed a clinical rotation in the University of Canterbury Speech-language Therapy Aphasia Clinic in 2014.

### **What will happen in the study?**

The study will involve two rounds.

The first round involves completing a questionnaire about you perceive makes it hard (i.e. barriers) and what helps (i.e. facilitators) adults with aphasia and their family members to access and take part in the University of Canterbury speech-language therapy aphasia clinic.

The information collected during the first round will be used to develop a second questionnaire about the most important barriers and facilitators that affect access to the aphasia clinic.

You can fill in the questionnaires via e-mail or in a paper format depending on your preference.

You will also be asked to complete a brief information form about the number of clients you saw at the clinic etc.

You can return all these forms via email or post.

### **How long will the study take?**

The first questionnaire will take about 20 to 30 minutes to complete.

The second questionnaire will take about 15 to 20 minutes to complete.

You can complete the questionnaire at a time that is convenient for you.

### **Where will the study take place?**

You will fill out the questionnaires at a location of your choice.

### **What are the benefits of participating in the study?**

Your participation in this study will help researchers understand how to improve the accessibility of the University of Canterbury speech-language therapy aphasia clinic. However, there may be no direct benefit to you.

### **What are the risks in participating in the study?**

There are no significant risks if you choose to participate in this research.

### **How will confidentiality be maintained?**

The results of the project will be discussed in a thesis. A thesis is a public document and will be available through the University of Canterbury library. The results of the project may be published. Any identifying information about you is kept strictly confidential. Your identity will not be made public without your prior consent.

Strict confidentiality will be maintained at all times.

All information about you will be kept in a locked cabinet in the Communication Disorders Department, The University of Canterbury.

All electronic information about you will be stored in a password-protected database on a computer in a locked office in the Communication Disorders Department, The University of Canterbury.

Only the research investigator, Dr. Howe, Dr. Rose and research assistants will be able to access the information. Although Chris Wyles is also a research supervisor, she will not have access to specific information about you in this study.

After the investigation, raw data will be stored in a locked cabinet in a locked office in the Department of Communication Disorders at the University of Canterbury for five years and then destroyed.

### **Can you withdraw from the study?**

You can withdraw from the research study at any time, without reason. You are under no obligation to the researcher. Choosing not to take part in or withdrawing from the study will not affect your relationship with The University of Canterbury. If you withdraw, you can request that the investigator destroy all information already collected from you.

This project is being carried out as a requirement for MSc in Speech and Language Sciences by Cassandra Chow under the supervision of Dr. Tami Howe, who can be contacted at: [tami.howe@canterbury.ac.nz] and Christine Wyles, who can be contacted at: [christine.wyles@canterbury.ac.nz]. They will be pleased to discuss any concerns you may have about participation in the project.

This study has been reviewed and approved by The University of Canterbury Human Ethics Committee. If you have any complaints, please contact: The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

Thank you for your interest in this research study.

Cassandra Chow, Grad.Dip.SLT, B.A.(Hons)  
MSc Student, Ph. +6421889426  
Communication Disorders Department  
Telephone: +6421889426  
Email: cassandra.chow@pg.canterbury.ac.nz



## **Consent form for student speech-language therapists (on UC letterhead)**

### **Barriers and facilitators that affect access to the University of Canterbury speech-language therapy aphasia clinic**

I have been given a full explanation of this project and have had the opportunity to ask questions.

I understand what is required of me if I agree to take part in the research.

I understand that participation is voluntary and I may withdraw at any time without affecting any services I receive from the university. If I withdraw, I can ask for my information to be destroyed.

I understand that any information or opinions I provide will be kept confidential to the researcher, her supervisors and research assistants. Any published or reported results will not identify the participants.

I understand that all data collected for the study will be kept in locked, secure facilities and password protected electronic form and will be destroyed after five years.

Only the researcher, Dr. Howe, Dr. Rose and research assistants can access the information. I understand that although Chris Wyles is also supervising, she will not be able to see specific information that may identify me.

I understand that a thesis is a public document and will be available through the University of Canterbury library.

I have/will be given a copy of this form.

I understand that I can contact the researcher Cassandra Chow [[cassandra.chow@pg.canterbury.ac.nz](mailto:cassandra.chow@pg.canterbury.ac.nz)] or supervisors Tami Howe [[tami.howe@canterbury.ac.nz](mailto:tami.howe@canterbury.ac.nz)] and Christine Wyles [[christine.wyles@canterbury.ac.nz](mailto:christine.wyles@canterbury.ac.nz)] for further information. If I have any complaints, I can contact the Chair of the University of Canterbury Human Ethics Committee, Private Bag 4800, Christchurch ([human-ethics@canterbury.ac.nz](mailto:human-ethics@canterbury.ac.nz))

- ☐ I would like a summary about the research findings sent to me at the end of the study.

By signing below, I agree to participate in this research project:

Signature:\_\_\_\_\_ Date:\_\_\_\_\_

Participant Name:\_\_\_\_\_

Email Address:\_\_\_\_\_

This form may be returned by via email/post to Cassandra Chow.